

# Stroke Pizza

A Collection of Personal Narratives from  
Cavernous Malformation Survivors and Caregivers

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Amy Meng  
Kristen Fowler  
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Darla Clayton  
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Welcome Reader,

In early 2025, as Rare Disease Day approached, the Alliance to Cure Cavernous Malformation Community began looking for a short story collection to read together for our book club. We found powerful anthologies representing many rare conditions, but none included a story about cavernous malformation.

So we decided to write our own.

Over the course of the year, members of our CCM community met monthly to write, share, revise, and encourage one another. What began as a book club idea became something much more: a space to reflect, to laugh, to grieve, and to put words to experiences that are often hard to explain.

Along the way, something unexpected happened. Writing together became its own form of support. Participants stretched, reconsidered, remembered, and sometimes surprised themselves. The process proved just as meaningful as the finished pages.

*Stroke Pizza* is the result of a year of courage, creativity, and community.

We're grateful to the writers who trusted us with their voices.



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# Out of Office

By: David Meyer

Up until this point, I have been hesitant to write down my story. Not because I didn't want to share it, but because I tried my best not to think about the moment that my brain bled. I felt like if I did, it was like it was starting all over again. The tingly feeling in my head like I had just been hit by something, the confusion, the overwhelming feeling that something was really wrong. Like, really wrong.

I try to think about what it felt like, but it was such an unusual feeling, I don't even think I can explain it. It felt like my brain was short-circuiting, and the thought did cross my mind that I was about to die. It was that unusual. And I'm not new to pain. I know what hurt feels like. This wasn't that. I didn't want to believe it, though, so I thought I would take a minute and sit down to see if I felt better. I then felt an electrical feeling go up my neck into the center of my brain, and my vision "cracked" into two.

This is the part that would start to make me really uncomfortable when I would think about it; I would start to feel overwhelmed and experience an adrenaline-rush feeling. I am still unsure if this feeling was a panic attack or an atypical migraine, but I am finally being treated for atypical migraines after four years of not knowing. Whatever the case, I am now able to talk about it without spiraling, and I no longer feel the need to unlock the front door when I'm alone in case the paramedics need to get in. Therapy, time, my current medication regimen, and my medical team have helped me get to this point.

That day had been pretty unremarkable, really. I work in information technology, and I had to go out for a call to replace a hard drive in a computer. On the way back, I stopped for lunch at a NY pizza place that I have now nicknamed "Stroke Pizza" and headed home. I ate lunch, checked my emails, and then had a midbrain hemorrhagic stroke at the age of 45 years old for no apparent reason. I called 911 calmly, as one does, gave them my details, and explained that I thought I was having a stroke, having remembered the BEFAST warning signs from when my grandfather had a stroke years prior.

There were some firemen getting gas close to the house, so they got there really fast and sat with me while the paramedics arrived. I remember being pretty "with it," just really confused and thinking, no way am I having a stroke right now, I am only 45 years old! I also didn't know this at the time, but my wife had seen the firemen on the Ring camera and had no idea what was going on. She must have been flying home, though, because I heard her talking outside the ambulance just as we were about to leave for the hospital. I remember asking them in the ambulance what my blood pressure was, and them answering 170/140. I was like, "Holy Shit! Take me to the hospital!"

At the hospital, I called my mom and grandmother and told them what was going on and that I was OK. I remember someone confirming that I was having a stroke and then hearing someone ask if I could squeeze their hand. The next thing I remember was waking up, startled, in a CT machine. My short-term memory must have been damaged because I only remember bits and pieces from the hospital, mostly uncomfortable things. I remember having to poop in a chair with a bucket, probably because I was embarrassed and felt bad because the nurse had to clean up after me. I remember eating squash, which I really don't like.

The worst thing, though, is the only time my family left my side. I have a memory of a whole Neuro team standing at the foot of my bed, I think explaining what happened to me and what the next steps were, but I have no idea what they said to me. I just have an image in my head of a bunch of doctors standing at the foot of my bed in the ICU and that's it, nothing! In fact, we had to schedule a follow up appointment a few weeks after I was released from the hospital to find out what the plan was.

I was originally scheduled for surgery on the advice of the neurosurgeon who was on shift when I was in the hospital. I think he was probably a doctor that had not performed too many surgeries that were in eloquent areas like the midbrain. They wanted me to go home and rest for two months to give my brain time to heal and for the inflammation to go down before I would have surgery. His partner, Dr. Fukushima, who was in Japan at the time, was a world-renowned neurosurgeon who would perform the surgery and take the malformation out to prevent any future bleeds. We looked him up and found tons of positive information about him that made me feel as good as one does about having brain surgery.

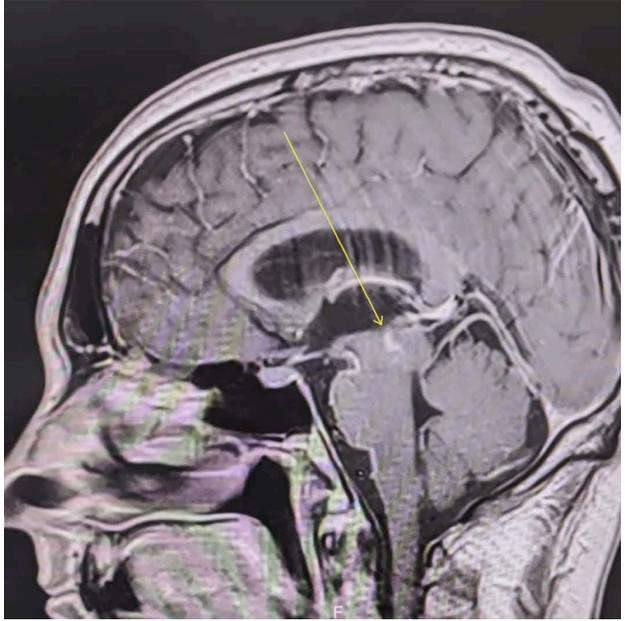
Two months later my parents flew down to NC, rented a house to stay in, I went through preop and when Dr. Fukushima finally looked at my MRI after arriving from Japan, he cancelled the surgery. He said, "We aren't going to operate because it doesn't come to the surface and it might not bleed again, so surgery is too risky right now." I was devastated at first. Why did they let me think I was having surgery for 2

months!? There was no way I could live with this. I have obsessively spent the last two months reading every possible thing I could read about Cerebral Cavernous Malformation (CCM), and I know I have a 30-50% chance of having another rebleed in my brainstem, one of the worst places to have a stroke. I was a hypochondriac to begin with, and I was just diagnosed with what then seemed like the worst thing I could have: something wrong with my brain.

I don't remember much over the next year. I think I slept a lot. I went to a lot of doctor's appointments. I worked on getting better, I ate healthy, and I started walking and exercising as much as I could. I remember trying to go to the grocery store one time and my double vision and peripheral vision were so bad it looked like the aisles were bending as I was walking down them. I didn't go to the store for a while after that. I was in a constant state of panic, worrying about this happening again.

I found a Facebook group called the Alliance to Cure Cavernous Malformation and started going to the weekly support groups. Learning from others' experiences helped me so much. It gave me hope. I started going to therapy, too, and started learning how your brain deals with trauma. I found out what medical PTSD is. I started volunteering for the Alliance to help give back to others what they had given me: Hope.

I am so grateful for this community that we have, and I know together we are going to find a cure. Four years later, I'm not going to say I'm glad that my brain bled, but I will say that I do appreciate things a lot more now, and my life is a lot richer than it was because of it. Stroke Pizza may be permanently off my meal plan, but lots of other good things found their way onto my plate. I definitely don't want to go through another hemorrhagic stroke, though.



# Accepting Uncertainty

By Amy Meng

Before my diagnosis, I believed that if I made the right choices, life would follow a predictable, safe path. I thought that effort, care, and devotion were enough to protect me and the people I loved. I did not think I was invincible, but I believed I was being carried along a path where responsibility and diligence kept disaster politely at a distance. I did not yet know how much of my sense of safety was built on certainty, or how quickly that certainty could unravel.

By all outward measures, I was doing everything “right.” I married a doctor. I earned a Master’s degree in Public Administration. I worked for a nonprofit in Washington, D.C. We welcomed our first child. Later, we moved again as my husband prepared for deployment to Iraq. I worried about how the separation would shape our young son, and whether my husband would return home safely, or as the same man. I never imagined how quietly, and completely, my own life was about to change.

One evening, while solo parenting our two-year-old, I was picking up toys and singing the “Clean Up” song when I swung my head up and struck a heavy TV armoire. The room spun, stars circling. I lay down for a moment, but my son still needed a bath, and bedtime still waited. Like so many military spouses, I told myself I was fine and kept going.

Over the following weeks, my health began to fray. Headaches came first, then dizziness, then a fog that stole words and sleep. One day while driving, a sudden, strange electrical whooshing surged through my head. The world blurred. My arms and legs turned heavy and unreliable. Somehow, I managed to pull the car over with my son in the back seat. I remember gripping the steering wheel and thinking, Not like this. Not with my child here. After that day, fear rode with me every time I got behind the wheel.

A CT scan suggested a brain bleed, and I was urgently sent to Kansas City to see a neurosurgeon. I waited all day in the emergency room, surrounded by the small, ordinary sounds of other people’s crises. When I was finally seen, I was told the

neurosurgeon specialized in the spine, not the brain. I was advised not to drive, not to take pain medication, and to read a book to help me sleep. I went home confused, frightened, and still in pain, feeling, for the first time in my life, unprotected.

The radiology report said I had cavernous hemangiomas, also called cerebral cavernous malformations, or CCM. Because the disease is rare, no one seemed quite sure what to tell me. I was given contradictory explanations, vague warnings, and a month-long wait to see a specialist. During that month, my body and mind unraveled. I had panic attacks no one could confirm were not seizures. My right side weakened. One neurologist looked at me and said she could not help me.

Eventually, I saw a neurosurgeon who confirmed the diagnosis. One lesion in my frontal lobe, the speech center, had bled but did not require surgery. I was told they could “leak” and to come back in six months; a sentence that would become a kind of refrain in my life.

At the same time, my husband was making the dangerous journey home from Baghdad. When he returned, anxiety had taken up residence in my body. The life I thought I was living, the safe, carefully constructed one, was collapsing. I was afraid of my own brain and grieving the body I used to have. I wanted to be the one giving support, not the one who needed it.

That uncertainty stretched on for years. I lived with right-sided weakness, debilitating migraines, and the invisible weight of medical trauma and PTSD. I struggled to trust doctors, and even more, I struggled to trust my own body. I began therapy, not to fix my body, but to learn how to live inside it again. That was the beginning of discovering a different way to live, not anchored in control, but in learning how to let go.

Slowly, I learned to notice my emotions and ask for what I needed. I learned to loosen my grip on the exhausting illusion of control. I took up photography to retrain my eyes to look for beauty instead of scanning for danger. I learned how to protect my energy and set boundaries. I learned that life does not promise safety, but it does, sometimes, offer moments of meaning, connection, and unexpected grace.

Years later, genetic testing revealed that I have a CCM2 exon 2–10 deletion. Through Alliance to Cure Cavernous Malformation, I contributed my DNA to research at

Duke University. I found people who spoke this strange language of MRIs and lesions and waiting, and I found pieces of my family story I had never known. For the first time, my suffering had context and a community.

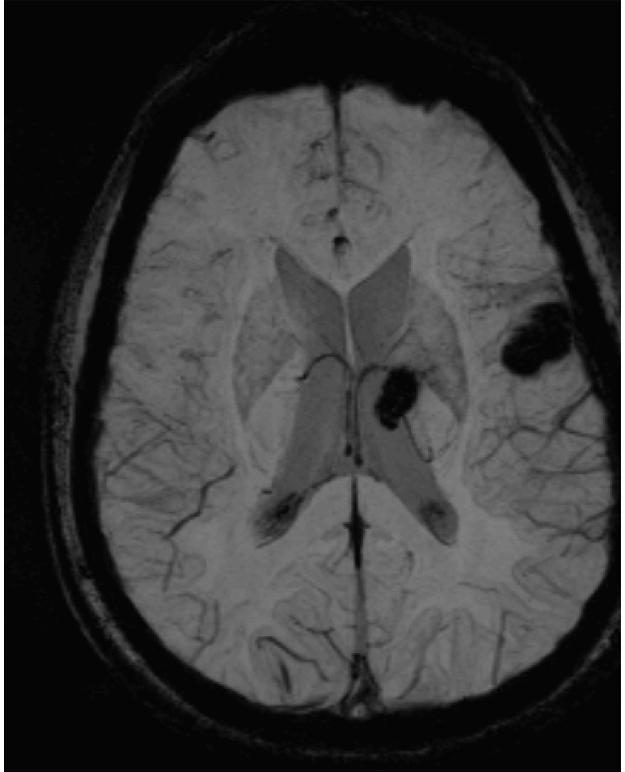
The pandemic layered new uncertainty onto everything we were already carrying. Since I have the familial form of the disease, we made the difficult decision to have our three sons tested. When the results came back, I was stunned.

All three were negative! I wept, not from fear, but from release.

They will not grow up with annual MRIs, lesion growth, or looming surgeries. They will not be told their CCMs are too much to be measured. They will not have to explain a rare disease to confused doctors or friends. They will not stare at images of their own brains and wonder which dark spot might take something precious from them. For my family, the uncertainty stopped with me.

I do not know what my own future holds. But I do know this: I have lived through what I once thought would break me. I did not get the life I planned. I got something quieter, harder, and deeper, a life built not on certainty, but on learning how to live honestly inside what cannot be controlled.

CCM is a rare disease marked by uncertainty. Alliance to Cure Cavernous Malformation gave me language, knowledge, and companions for this road. With time, and with that support, I learned that accepting uncertainty does not mean giving up; it means walking forward anyway, with strength and courage.



# My Life With Cavernous Malformation

by Kristen Fowler

I was born in the small town of Fullerton, California. My childhood unfolded in a typical suburban neighborhood, one brimming with towering trees and the joyful chaos of neighborhood kids playing outside. My home was a ranch-style house that I shared with my mom, dad, older brother Bryan, and my fraternal twin sister, Katie.

When my mom was preparing to put Katie and me in kindergarten, Katie was admitted without problem. In terms of the basics of what a child should be aware of at that age, my learning skills deemed to be a little lax and it was decided that I had to start preschool over. From that day forward, I would go on to feel inferior to my sister for years because she excelled in school while I always had to struggle to get ahead. But back when I was younger, I just went to school as I was told to, in whatever class I was assigned.

When I finally was admitted to kindergarten, for a while, I was an outgoing little girl. I wore a sweet little dress to school every day, my hair was always down, and recess meant running in the fields with my friends while the boys would chase us.

As I went on to first, second, and third grade, things proceeded in a pretty ordinary way and I started to feel more accomplished. At the same time however, sometimes things were askew. An example would be that the feeling and ambiance of life would alter from time to time. It was subtle, but every year, my outlook on the world seemed different. My mind's eye was different. I usually noticed it at recess. I'd look around the playground and feel as if I were seeing things through another person's eyes, with a different perspective on how everything looked visually and felt emotionally. I especially remember one moment, when I was in recess and I was looking at my school's playground and then, suddenly, everything suddenly seemed more somber and had a darker hue to it. The day felt melancholic. I felt a bit removed from everything, as though the day had acquired a new, darker dynamic and I was just living in it.

Each year would pass, and I would be at recess again and stop when I noticed that my world had changed. I would physically feel a strange, intense vibe creeping up on me. Grades one and two went by, and my world changed with it. That's the best I can describe it. As I look back on things, these shifts in perception should have been more suspicious to me, but I didn't want to tell anyone because I was embarrassed at the idea that I would be thought of as weird, and would be a burden to my parents. My parents just thought that I was a little lax on things, simply because every kid is different. My fraternal twin sister was more advanced than me because she had skills that I just didn't have. However, I think that I knew that I was somehow dissimilar on a different level, and I was scared of that. This phenomenon, however, wasn't the only thing that was confusing and suspicious.

Over time, my once-extroverted nature started to fade and I wasn't as good at being social in class. I excelled at the artistic and creative aspects of learning, but mastering the more factual subjects was a struggle. Reading became a labored chore. My grades started to slip downward. I was also sleepier in the morning; my hair went into a ponytail because I lacked the energy to do anything else. While I noticed these differences in perception, skill acquisition and basic energy levels, I didn't understand *why* they were happening. Just around the corner of those early years, however, these changes would all have an explanation.

There was a reason why I wasn't as capable as my fraternal twin sister in school. There was a reason why the outlook of life seemed to change to me at times. There was a "why" behind my failing grades, my sense of over fatigue, my indifference to my fellow schoolmates. Those reasons were answered when I was nine years old.

In the middle of the year 1991, when I was in the third grade, and nine years old, things took a hard left turn in my ability to function in school or anywhere else. I was feeling "off" and, when I went to my pediatrician, he thought that I had the flu because I was throwing up and had a headache.

A day or two later, I was at home with a touch of vertigo and told my mom I was seeing two of her. That night, at around 7PM, my mom told me that we were going back to the pediatrician's office. It was strange; a flu diagnosis was usually a one-stop shop kind of thing, and going to the doctors' at nighttime was odd because, I thought, the

pediatrician wasn't a doctor that worked past about 5 pm. My mom was adamant that we were going to the doctor's though, so I played along.

Soon, as we set out to get medical help, my symptoms accelerated. It became obvious that something was very wrong with my situation. I didn't have vertigo, I just couldn't stand, and my thinking became labored and slow. I needed to go to the ER.

At the ER, things remained jumbled up and foggy. I remember getting a CAT scan of my brain (MRIs weren't widely used then), and I was put on some sort of table while lots of doctors stood around me and talked to each other about what was going on and what should be done. They moved me from room to room, while my future was in the balance.

I don't remember being told anything at the time, but, later on, a doctor explained that I had a huge number of lesions in my brain and that one had bled a good amount in the pons of my brainstem. "Whatever the pons is," I thought.

I don't recall the details of any of this because I was having blackouts at the time. The doctor also said that I was probably going to need surgery to take out the lesion in my brainstem. It was disclosed that I had a venous anomaly. The doctor said that venous anomaly was called AVMs (arteriovenous malformations). AVMs are a venous anomaly, but, this was a misdiagnosis, and this misunderstanding wouldn't be corrected until I was twenty-five years old.

The height of my worries weren't the blackouts though. The pivotal problem reared its ugly head a day later when I became paralyzed on the entire right half of my body. I was having dizziness, fatigue, brain pain. I called the pain in my head "brain pain" because I'd had headaches before, and this wasn't that. I was smelling things that weren't there (which turned out to be a seizure). The most impressive computer I would ever own, my brain, had to be rebooted, and the information and understanding of things were coming in slow.

Word recall was a big problem and the ability to make sound judgments was highly diminished. The paralysis made it very difficult to speak, let alone have people understand me.

The wires in my brain were still figuring out how to plug themselves in correctly. I laid there with my fatigued cerebral dukes up. This was my life for a few days until my parents gave the ok for the neurosurgeon to take out the lesion in my brainstem because they hoped it would fix the paralysis. This was an extremely hard decision for everyone to make because surgery might bring on a host of complications and finalities including, the worst, of course, which was death.

I don't remember a lot of details from the surgery day but, when I woke up, I was told the surgery had worked, but now I would have to work really hard to get the full movement of my body back again.

I was released from the hospital and I returned to school. I knew even then that kids are scared of things that they don't understand and I wasn't sure if they would accept me after my surgery. However, I made sure to explain the brain bleed and what I went through to my classmates to help them grasp the idea. I felt like I was welcomed back more easily because of that.

Soon afterwards though, when I was ten, eleven, and twelve, I had "Gamma Knife" surgery. It was a brand-new surgery that used gamma radiation (that only resembled knives) that would go through the brain to destroy some of the lesions. The surgeon hoped to get rid of a bunch of the lesions— even if not all— at each stage of the surgery, so I would have a better quality of life.

For each surgery, I'd get mild anesthesia, and they would screw a metal crown that reminded me of an erector set, into my head at four corners of it. The surgeons that were helping me, would contort the crown into a position so that the radiation "knives", could reach the precise lesions they were aiming for. The surgeons did this several times, leaving the room in between sessions, so they, themselves wouldn't absorb the radiation. They would allow me a few minutes after each session for me to gather myself.

This Gamma Knife surgery happened three times. Once every year, for three consecutive years of 1992, 1993, and 1994. I cried only once, after the last surgery. It was very traumatic, but I believed it to be necessary. It turned out, however, that these

gamma knife surgeries were a huge mistake for me, although nobody had the scientific knowledge to predict this at the time.

Radiation, it turns out, is helpful for some kinds of cancer treatment, but *can* be quite harmful for cavernous malformation, which was not even diagnosed for me at the time. A year or two after the Gamma Knife surgery, my neurosurgeon discovered the completely devastating news that, because of the amount of radiation that I took in for the three surgeries with number of lesions removed within a short time in between, all of the lesions that the surgeons had taken out had regrown and multiplied. The ones that were taken out in the past, or that would be removed in the future, would do the same.

This news put things into perspective for both me, and my family. Having gone through paralysis at such a young age. Quickly afterwards, having three surgeries that were new in performance and catastrophic for my livelihood. It was an expensive and precarious illness I had. It felt like I had a physical price I'd have to pay in the future, and no idea when I would have to pay it.

After these Gamma Knife years, things were pretty quiet on the western front, so to speak. I even made it to the end of high school. I had past most of my final exams and I was ready to graduate. Then, right before my graduation, things went awry again. It all started when I experienced the worst neck ache I could imagine. I could tell that I was extremely depleted and nonsensical. Miraculously, I passed my last exams, but my symptoms kept accelerating.

Dazed and confused, I really wanted to get the experience of graduation, because I didn't know if or when I would get to have a major moment like this again. So, despite these worrisome warning signs, I basically made myself go through walking in my graduation ceremony, going to dinner with my family, and then going to grad night because I wanted to keep that part of my life for myself and make memories. I made myself do all of this while it was as if I were on another planet. It went ok enough. I got the experience I wanted for my graduation.

Grad night was being held at my school with lots of fun games and appetizing looking food but, I was too nauseous, and beyond disoriented to enjoy it. I'd never been drunk but, I imagined, this was it's ominous cousin. Around about midnight, I had to call

my mom to get a ride home when I finally had to admit to myself that I needed to slow all the way down. I had to accept that my brain was taking over and I needed help. It's one of the hardest things to learn how to do: to ask for help.

The next day I went to the ER and found out that I had a big bleed in my thalamus. When I have a big bleed in my brain, whatever doctor I'm talking to always wants me to describe the symptoms to them. But how do you do that if you are not in your right mind? Because, after all, your brain is having the kind of problem that makes describing symptoms to your doctor practically impossible.

For me, a brain bleed is a feeling that is so easy to forget, but SO easy to remember. It feels like there is sun-fire orbiting your brain. There are comets coming out of nowhere. There's a big black hole at the center of it covered in dust and smoke. But it's difficult to explain all of that to a doctor and make sense of it when there is a galaxy forming in your head.

At the ER, I was having an ongoing out of body experience (a seizure). It was as if the whole world were a movie. It was as if I were watching myself, watch myself, watch the world. In this awake comatose state I was transferred to the ICU. My close family and neurosurgeon were there. It was extremely odd. When someone asked me a question, first I had to realize that they were talking to me, then I had to make my body answer it.

The answer that came out sounded as if it were coming out of somebody else's mouth. I just wanted everybody to go away. Not because they were there, but because I wasn't.

The first night at the hospital went like this. Brain pain was all over the place. Burning pains, stinging, shooting, stabbing, nerve pains, muscle pains. All the feels. The lights were off in my room and, most of all, I wanted to do something, anything to help the situation or to make myself feel just a smidgen better. I wanted to sit up or breathe deeply or *something*. I wished I could sleep. But I was either in too much pain or too weak to do any of those things. I couldn't even count on my doctors for that time because they needed more information before they would have any idea of how to help me. Not moving and resting my brain and my body was the only thing that I could do to

help myself because it was letting the process happen. I nervously laid there while hot tears stained my face. It was crushing to know that the only thing I, or anybody else, could do to help me was for me simply to just lay there and take it.

My internal computer needed to be rebooted again and it was going to more complicated this time. I knew I was going to get more brain damage, but it was hard to say how much healing would eventually happen after about a year of recovery. My computer shutting down before rebooting itself meant that my sense of self went away. I was living with a stranger. A stranger with the weirdest beat-up brain sensation and living half alive.

The thalamus is a really difficult spot to have a bleed because it is a delicate, fierce, deep brain structure. It sits up on the brainstem, kind of like the top of mushroom. It is really hard to operate there, and the cons outweighed the pros for another surgery for me.

I stayed in the hospital while some of the blood reabsorbed. Gaining the minimum of movement would be what was necessary to be able to return home from the hospital and, once I had enough of my faculties back, I was released.

I went home and was driven to therapy appointments regularly to retrain my body's vitality. I needed to learn to walk and use my hands *again*. When I had my first big bleed I had done this. Now that I had this second big bleed, I had to get back on the proverbial horse.

The brain controls one's body, and when the brain is damaged, movement and feeling can be taken away. Once discharged, the real work begins for a patient: Physical Therapy (PT) for the legs and Occupational Therapy (OT) for the arms and hands. Physical therapy meant moving my body to help send my brain information, and vice versa. It's a mutually exclusive relationship and it spins the cycle of movement.

I think that walking again feels sort of like an evolution. I personally would liken it to starting out like a worn out and feeble Gollum from "The Lord of the Rings", then moving on to a rheumatic-like Frankenstein's monster, then on to a zombie as it lurches its rigor mortis-like muscles in a staggering forward progression, then to a drunk person who can walk pretty well, but not without some balance issues, then evolving in to a hunched

over teenager, young but slumped, and finally, developing into a full forward walking person. See example pictures here.



For me, learning to walk again was all about balance, structure, endurance, and a lot of patience as my brain and body tried to adapt with each other, leaving more than plenty of room for inaccuracy as my body struggled to do what it needed to do to become more able.

The other ability I needed help with, had to do with my hands and fingers. I needed them to move naturally again, so I could take care of manual tasks. In other more scientific terms, using my fine motor skills. Buttoning buttons, turning handles, working with any form of tool or machine. For all of these things, I needed fine motor skills and the use of my arms. If I wanted a better chance doing any of these essential daily tasks, occupational therapy is where the muscles and abilities for these things were to be re-learned.

When I went to occupational therapy, the therapist put a handful of beans in front of me. They weren't cooked, and thus were a hard consistency. I was told to pick one up with my left hand's pointer finger and thumb. I was taught that this exercise would have my hand and fingers working together to complete tasks and that by trying to move several parts of their anatomy, my fine motor skills would become strong.

I imagined that this set up looked like a miniature hill of beans, and my fingers were like a crane that was supposed to pick them up. Unfortunately, my "crane" had too much spasticity (aka rigidity), so that was my challenge there.

This is why, for instance, some brain patients look like they're babies just learning to use their fingers for the first time, because, in a lot of ways, they are. Once I could

move my fingers though, I could attempt to use them by picking something up, zipping up a sweater, pointing at an object. Firstly, for me, it all added up to hill of beans.

On the day I first successfully picked a bean, I imagined the people around me being aghast by what I was able to do. I hoped that they were giving me the correct amount of gasps and beginnings of applause as they witnessed my capabilities, my competent wrist, hand, and fingers holding my almond sized bean, as I thought, are you seeing this crap?!

I was so thankful. Because my body came back. I came back. I thought that this is why someone goes to Physical and Occupational Therapy: to make one's body become stronger and more whole again. My brain, my body, and my self came closer to becoming one.

Becoming one is different depending on a person's circumstances. A big example of this would be when I had another bleed in my thalamus when I was twenty-five. I went through having my bleed and two brain surgeries to extract the insides of a cyst that the bleed had turned into. I had loss of feeling and balance. After I relearned to walk again, I had a recurrence of symptoms though, and my mom and I didn't know what to do with it except go to the ER again.

I'm a firm believer that sleep is medicine. Never have I felt so bad that sleep didn't make me feel just the smallest bit better. Sleep heals. I was counting on that because my prescription medication didn't seem to be helping as much as usual. However, when I went to sleep one night, just as I was about to fall asleep, my upper body would jolt forward. This symptom happened every night, sometimes an entire night or two. This symptom wasn't just a deterrent to my recovery. The bleed took my sleep away and, therefore, it took my important medicine away. I felt like my sanctuary was stolen from me and, heartbroken, I grieved it every time I woke up.

With time, it was surmised that my symptoms were the sign of *myoclonus*. The term describes exactly what I was experiencing. A diagnosis has always been a good thing to me. It is either the effect of knowledge being power or, sometimes, it means that there is a solution to the problem. In this case, it was, thankfully, both. Because my neurologist knew what the problem was, he knew of a medication that would be best for my specific

situation. Which only makes sense, because medications are a neurologist's expertise, and each patient is different. I was prescribed *clonazepam* and, to my exhausted relief, it worked. Such a lot of trouble to realize this though.

After all of these things that went on during my third big bleed, I wanted to discover the reason for all of my life's brain troubles. There had to be more to it than my doctor's simply shrugging their shoulders. For an answer such as this, I went to see a geneticist. My geneticist found out that I had been misdiagnosed with AVMs my whole life. He found that I actually had Cavernous Malformation, specifically with the CCM3 (PDCD10) gene. This is what had caused all my catastrophic ailments. This was real and I treasured it. It was the best present I thought I'd ever been given.

What's more, my geneticist found a support group accompanied by doctors that were actually studying our disease. The support group was the Alliance to Cure Cavernous Malformation. To say I was happy to discover this group is a gobsmacking understatement. Here, I found more answers than I had ever hoped for. I now knew people who had what I had. I knew people who understood the haphazard insanity of the disease, and now, they were all my friends on Facebook. I sobbed with happiness.

Thank you, God, I thought.

Now I am forty-four years old, and really proud of my years on this Earth because I certainly earned them. I've been through a lot since my third big bleed. This was another large bleed in my brainstem, where I had very hyper-realistic dreams, and developed a new symptom called "central pain syndrome" [where a person who has had problems with their brainstem or thalamus (I'd had both) presents body pains and numbnesses sporadically). I won SSI disability, which was a hard won, and long fight.

What I've dealt with, I've learned to get over. Time and effort have allowed me to heal a lot of the broken parts of my soul through self-contemplation and pride in my perseverance. My doctors have been Godsend. My family members are all my angels. My knowledge of my disease was due in no small part to the Alliance to Cure Cavernous Malformation.

Having gone “through it” a number of times, it really makes me appreciate what I do have. I can still talk, and say words like “ostentatious.” I can still walk around like I own the place. I can order tasty food, instead of the hospital’s miscellaneous brown meat.

Yes, sometimes I’ll forget words, like the word “year” or my niece’s first name. I’ll walk straight into a pole that I didn’t see on the street. I’ll maybe bite my tongue as I eat a meal. But I do all of these things by myself. Life didn’t take everything away from me like it could have, and life is good.



# Beyond the Before

By: Rebecca Kneale Gould

*Back in the days when everything seemed so much clearer  
Women in white who knew what their lives held in store  
Where are they now, those women who stared from the mirror?  
We can never go back to before.*

— “Back to Before” from *Ragtime: The Musical* (1996 Lynn Ahrens — lyrics; Stephen Charles Flaherty— music)

*Before* (prior to October 2024). Before, I could pack a week of “things” into a single day: tend sheep, teach, hold office hours, respond to an endless flow of annoying email, tweak a few paragraphs on my latest publication, meet with a promising thesis advisee, go to a department meeting, drive home, help with the sheep, figure out dinner, then drive back to the Havurah House to lead my monthly women’s chant group. My spouse and I used to joke about this. “We live in the middle of nowhere Vermont! How is it that we are so damn busy?”

*Now* (December 2025). Now, I can often do only a handful of things within a given day: feed the sheep (but not by myself), check email (if I can handle screens that morning), read (for about an hour or so, then it’s time to refrain from further input). When it works, I’ll take a stumbly kind of walk to make sure that I’m getting exercise and take care of some of the household basics.

Some days are better. Some worse. Driving any significant distance still feels mostly beyond my capacity. It’s not that I *can’t* drive; it’s that the cognitive cost of concentrating that hard for the sake of everyone’s safety is generally not worth the price I have to pay once I get home. If I choose to drive, I have to “un-choose” something else. Every day involves a set of careful calculations and I was never very good at math.

All of this should improve in time. After all, I am miles ahead of where I was a year ago and that is definitely something worth celebrating as I light the Hanukkah candles. But “should” is a slippery word and “in time” is not the same as *Now*.

I haven't lost my independence *per se* and for this I feel extremely grateful. Many of my newfound CCM (Cerebral Cavernous Malformation) friends have much greater challenges to negotiate. Comparatively speaking, I'm in decent shape. But still, most days it feels like I've lost the person who I once was.

My spouse and my dearest friends insist that this is not so— that I am still my essential self, perhaps even a “better” self in some ways, because I am not so rushed and busy. This is true. Thanks be to God, Mother Nature, and/or the Fates, the cerebral hemorrhage that literally knocked me down in October of 2024 did not hit those “eloquent” parts of the brain that coordinate speech and language. My former personality is also more or less intact, including those pesky parts that I might have been happy to leave behind. I am still me, just without the internal battery-capacity that I used to think of as my special superpower.

My beloveds are not *wrong* to offer reassurance and their reassurance means the world to me. But they are not quite *right* either. Anyone who has ever had a stroke knows all too well that the daily experience “on the inside” is almost impossible to convey to those “on the outside.” That's why we share our stories.

The particular story that I am telling here is one of curiosity, grief, frustration and persistence. It's about the unexpected task of walking into the unknown. I invite you to walk with me through this journey of Now, Later and Before. While one might think that such a journey would be linear, it is not. Nothing is exactly linear when something is wrong with your brain.

*Now.* When I can put some reasonable distance on the whole thing, curiosity keeps me going, as it has my entire life. I'm a scholar of the humanities by training (religious studies to be precise and “religion and ecology” to be even more specific, but that's another essay). Nevertheless, I find the brain to be truly fascinating. Before my hemorrhage, I relied on my brain for everything, but I knew so little about it. I love not

knowing, then learning, then knowing a little more and then— the key to most good teaching and scholarship— becoming even *more* aware of what I don't know.

While curiosity infamously “killed the cat,” it's always been a lifesaver for me. So, while reading and thinking is so much more exhausting for me now, it makes sense that I have turned my curiosity to my own situation. Fascination keeps me helpfully and healthfully distracted from the ever-unpleasant equation of *Before + Hemorrhage - Battery Power = Now*.

My hemorrhage occurred in the right frontal lobe, in the function-directing part of the brain known as the motor strip. (When I first heard this term, all I could think of was NASCAR.) The Thing That Went Wrong one day was that my left leg suddenly stopped working. Completely. I had to crawl up the grassy hill of my backyard and get helped into our car. The emergency room staff misdiagnosed me and — despite running a “stroke protocol”— ultimately argued that there was probably some kind of issue going on with my back. They ordered up a spine MRI that showed nothing beyond the usual decrepitude of a sixty-one-year-old ex-athlete. Shouldn't that rather unremarkable result have led them to do something more?

A head CT scan had been promised and then somehow cancelled. I still cringe looking at a provider's note in my chart that describes “mild left leg weakness” (which has led almost every other provider to replicate this initial untruth). *Who wrote that?* When I arrived at the ER, I could barely lift my left leg more than an inch off of the bed where I was lodged off and on for eleven hours. As those eleven hours wore on (without any food or water in case I needed— get this— *back surgery*), I was increasingly itchy to get home. Fear had turned to boredom and boredom to significant discomfort. I left the ER with a pair of crutches and absolutely no answers. In two weeks, I would be back in that very same ER, having finally received the brain MRI that I should have been offered the first time.

But I digress. (Misdiagnosis does that to you.) In the fourteen months since that memorable day in the ER, I've developed quite a fascination with the brain itself, the endless tiny machinations that the brain conducts, organizes and keeps track of every second of the day. Take, for instance, those thousands of electrical exchanges that

transpire in a single person-to-person conversation. In a conversation, you are processing audio and visual stimuli, making sense of non-verbal cues, taking in detailed content and, ideally, responding to your interlocutor with interest and empathy. I never used to think about it, but that's actually quite a lot! The under-appreciated brain is working its daily magic.

These days, this same bio-chemical magic is still happening (yay), but it takes much more neural effort. These neuro-electrical processes make conversations with more than one person rather exhausting, even when they are also delightful. After talking to people, I usually need to just go lie down. No wonder that going back to the college classroom feels very out of reach.

And what about the sheer miracle of neuroplasticity? The “scar” that I see on my most recent MRI represents dead neurons that are dead for good. But brain cells have their mysterious ways of getting around blockades, even blockades involving death. Rewiring happens! My left leg is working again. Rewiring enables one to move from *Before* into *Now*.

*Now*, thanks to great rehab coaches, a wonderful therapist, an amazing spouse, supportive family and friends, and some truly awesome trekking poles (gifted to me by said amazing spouse), I can move forward with two fairly functional legs. Occasionally, I can even trudge up and down up our local hillock— aspirationally dubbed “Mount Philo”— a two-mile round trip. True, I have to rest a week or so in between each attempt, but still, *I can get up there*. Last week, I even did it in the snow. The view is always wondrous.

And yet? And yet. There is still *Before*.

*Before*, there was Mount Washington: 4,866 feet with some of the world's worst recorded weather. True, I haven't “bagged” a four-thousand-footer in the White Mountains in quite some time. Nevertheless, in 2023, I still knew that it could be *doable*, in a weekend-athlete kind of way. Not anymore. “Not for *now*,” I remind myself. “Not ever?” I wonder.

Teaching and scholarship are the other mountains that I can no longer climb right now. I miss teaching terribly, although, to be honest, not the grading that goes with it.

Ever so slowly, I am reclaiming writing and that feels like a true reclamation of Self. But it's challenging now in a way it never had been before. Hard, slow and extremely fatiguing. But, like getting to the top of Mount Philo, it's exhilarating once it happens. That's *also* why I am telling you this story, so I can be something of a Writer once again.

The ever-cycling psychodynamics of Before, Right Now and Sometime in the Future manifest into a daily mental merry-go-round ride for me and I know I am not alone. All of my extensive spiritual training tells me to stay solely— and simply— attuned to the present moment. That's all any of us ever truly has, isn't it? Daily, I ask myself, "How hard can staying present really be?" Alas, we supposedly "thinking" (*sapiens*) humans have a bad habit of obsessing over the past and agonizing about the future, even when carefully trained to do otherwise. For the mind— a slightly different entity than the brain— staying present to *The Now* requires its own rewiring processes.

It's funny. I thought I was quite experienced with this "staying in the present" thing. I'm trained as a Spiritual Director and I bring contemplative practice into the classroom so that my stressed-out students can learn to take a deep breath every now and then. But now that I'm taking what feels like the Final Exam in Staying Present, I realize that I'm only just a step beyond novice. I watch my sheep sitting and chewing their cud for hours, a biological necessity for proper digestion. They are always and utterly in the moment. They know what to do. And I suspect that it's about more than digestion. They are my teachers.

So, what about *The Now*? Let's get back to curiosity. Right now, if I use my left leg too much on a given morning, it becomes much harder to read for any sustained length of time in the afternoon. And if I push my myself to do some semblance of reading and writing (the central part of my profession, not to mention my identity), I often find it harder to carry water buckets to my sheep the next morning. Now that *is* fascinating, isn't it?

What is obvious is also mysterious— at least to a scholar in the humanities. There is actually nothing technically *wrong* with my left leg. The problem is in my brain. Some of the neurons that once talked to my leg are permanently out of work. Others, I

suspect, are merely out to lunch. Reading and walking are caught up in some kind of interdependent neural-mitochondrial dance where one process directly affects the other. This would require a lifetime of study for me truly to understand, much less to explain. It's pretty cool. But it's also endlessly frustrating.

For me, the left leg has not been the primary challenge. For some medical professionals (not to mention evil insurance companies), it has been something of a distraction. The neurosurgeon whom I saw in the hospital was kind, competent and had a great reputation. But he seemed mostly interested in what was up with my leg and whether or not the lesion should be surgically removed. (We passed on the latter.) He never warned me that it would be hard to read— or to drive, or to talk to more than one person at the same time. A heads up would have been nice.

He also murmured something about six to eight weeks for recovery. He must have meant something like how long it would take for my left leg to go from totally useless to slightly functional, right? What *else* could he have meant? Because it's been over a year now and there's a big, wide, gaping chasm between *Now* and *Before*.

Some days it feels like the chasm is all that there is. When, however, I can stay focused on my renewed fascination with dendrites and axons, or the biochemistry of epithelial cell function – in other words, on what is intriguing, on what seems magical, it really helps. It keeps me less snarled up in the tangle of *Before*.

Cavernous malformations are themselves tangles of a kind, tangles of leaky blood vessels. Thinking of them reminds me of a common aphorism that I always misunderstood as a child. My mother would utter it frequently when my young siblings and I would descend into the blame game. "It takes two to tango!" she would remind us. But for the longest time, I had thought she was saying *tangle*, as in "it takes two to *fight*," which was basically the same message without the euphemistic metaphor of dance.

When I think of what the last fourteen months have been about for me, I find that "it takes two to tangle" is really a rather helpful dictum. Do I tangle with the tangle in my brain? That's what happens when I get hung up on the *Before*. But could I *tango* with that tangle instead? Is it possible to dance with the ambiguous present and the

uncertain future? Might I be able to quiet the questions about re-bleeds and quell my impatience for timelines that will precisely predict the return of my superpowers?

Ask anyone and they will tell you that dancing has never been my *forte*— and now, of course, I am more of a klutz than ever. But embracing nuance, complexity and uncertainty is what I think and write about all of the time. It's what I try to teach my students day in and day out, no matter what the topic or the text. I believe in this work and I am much better at it than I am at "Self-Taught Entry-level Neuroscience for Poets." Teaching people to get past false (and destructive) binaries is, in fact, *my thing*.

*Now* and *Before* is yet another binary. Quite possibly false. Or at least not the whole story. So, I tell myself, as I walk through my days of much fewer "things." I think of the wise words uttered by one of my teachers, Rabbi Shefa Gold, early on in my recovery: "You don't have to go back to who you *were* to become who you are becoming." I keep trying to live up to this dictum. But I must confess: mostly, I've just been trying to go "Back to Before." I can't really help it. I desperately want to return to the person who I once was.

This longing to reclaim my former self is not a fully conscious stance, nor one that I am particular proud of— after all, isn't it more inspiring to be a Master of Acceptance? Well, at least I'm working on it. And, of course, my process is hardly unique. These struggles just plain make sense when it comes to the human condition. The truth is: *the future may seem clear, but it is veiled for all of us*. Clinging to who "we once were" is a common practice for a reason. It can feel like the only waymark that there is— something akin to scanning a narrow ridge for trail-marking cairns in the thick fog on Mount Washington.

Who *am* I becoming?

If I can stop trying to go Back to Before, I just might start to find out.



# On Becoming & Other Acts of Badassery

By: Darla Clayton

This is a story about becoming. It took me a long time to realize that, but I guess that makes sense because becoming is always ongoing. It's not easy to see it occurring in real time. Margery Williams Bianco wrote about becoming in *The Velveteen Rabbit* and she said it so perfectly that I am sharing her words here:

You become. It takes a long time. That's why it doesn't happen often to people who break easily, or have sharp edges, or who have to be carefully kept. Generally, by the time you are Real, most of your hair has been loved off, and your eyes drop out and you get loose in your joints and very shabby. But these things don't matter at all, because once you are Real you can't be ugly, except to people who don't understand.

I set out to write a story about my kids and our struggles as a family with CCM, but in the end I wrote about my own becoming. So, here we go...

## ***Skating Through Life***

Trent getting sick was one of those moments that defined my life. It was like I was skating along on a frozen lake without a care, and even though I could hear the ice cracking, I didn't believe it would give way. So, I kept skating, carefree, not realizing I was about to fall through.

Darla of the past was a psychology graduate student, ambitiously working toward a double doctorate in clinical and school psychology (spoiler alert: just one doctorate made it to the finish line). I was driven, loved learning, and saw a future full of possibility. I had moved to the U.S. from Canada after getting married and enrolled in grad school at Indiana University of Pennsylvania, near where my husband lived. I loved working with kids and families and felt I was pretty good at it. I was tenacious and I knew where the future would take me, I wouldn't accept anything less. I've probably always had a smattering of ADHD, but I was highly motivated and had something to prove so I just barreled on despite my struggles.

I worked hard in school, got good grades, enjoyed time with classmates, and loved being home with my husband. I was feeling all grown up and domestic. Then one day, I

heard that twenty-four was the “optimal” age to have a baby, and wouldn’t you know, I was twenty-four! I don’t remember why it was optimal, but it stuck with me. I decided we should try to time things just right and have a baby around my brief early summer break. Even writing this I want to laugh at how young and naïve I was! Babies don’t follow calendars.

I didn’t get pregnant on schedule, so we planned to pause, and, of course, I got pregnant the next month. Trent was born smack in the middle of my summer intensive class, which led to the only C of my graduate school career. The professor insisted that class participation couldn’t be made up in any way, so despite taking an extra exam and getting an A, a C is what’s on my transcript (which I have, naturally, processed with complete emotional maturity and I harbor no bitterness whatsoever).

Despite the C, we were thrilled to welcome a healthy baby boy in June of 2003. Trent was a mama’s boy through and through. He loved to be held, snuggled and smooched. His eyes were the most electric blue. I took thousands of photos trying to capture them. I returned to school, pumping milk between classes in our clinic rooms. It was a lot, but it was manageable. Honestly, I was home with him more as a student than I would have ever been if I’d been working full time. He became a little fixture in the grad student offices. When he got a little older, he had one of those baby walkers that are notoriously unsafe (but we were on the ground level so I felt ok about it) and he would run the halls while I worked. Becoming a mom in grad school on purpose maybe wasn’t my brightest idea, but Trent was adored by all and I had no regrets.

### ***Treading Water with Skates On***

When Trent was around eight months old, I started noticing that he wasn’t using his right hand. His doctor said he was just a lefty, but it didn’t sit right with me. A month or two later, I mentioned it to my neuropsychology professor while Trent was with me at school. She was clearly concerned. Dr. Knicklebein told me that babies his age don’t show a hand preference and encouraged me to push harder with his pediatrician.

At Trent’s one-year appointment, we saw a different pediatrician, who gave him a thorough once over and agreed that something wasn’t right. I assumed it was a problem with his hand or his shoulder, so when he referred us to neurology, it rocked me. The

neurologist suspected an in-utero stroke and ordered an MRI to confirm it. The MRI was scheduled about a month after we saw the doctor and she told us we'd get the results a few weeks afterward.

I went home from that appointment and stewed! I looked through the thousands of pictures I had taken of my beautiful baby and could clearly see that he used to use that hand and then something had changed. I had a picture of him eating spaghetti where he had spaghetti all over his face and both his hands. A later photo of him showed something quite different: finger painting where the paint was only on one hand and one side of his face and one side of the paper. Something had clearly changed. I called the doctor and shared my observations and she told me that it was only when he started to have more purposeful movement that I noticed the change. She very patiently told me in slightly nicer words than this that I was a crazy first-time mom and I just needed to relax. And I tried. I really did, but I knew something else was going on. I contemplated taking him to the ER and telling them that he fell down the stairs and hit his head so they'd scan him then and there, but I didn't want to be crazy! So, I waited...

On the day of the MRI, I wasn't expecting anything major, I just needed to get through the scan and sedation (they put babies and little kids to sleep for MRIs because they can't stay still that long). My husband didn't even take the day off work, we thought it would be really no big deal. Luckily my friend Lisa came with me, for which I'll forever be grateful. During the scan, we started hearing pages: "So-and-so to MRI suite, stat" announced overhead. Several doctors were called in. I looked at Lisa and said, "That can't be for Trent... right?" His thirty-minute scan took far longer than it was supposed to, but I stayed calm. I'm steady. I don't overreact.

We headed to recovery after the scan so Trent could wake up. A young doctor came in and asked to speak with me. He told me that they had found a mass in Trent's brain. I was shocked and got a little defensive. I said, "He's meeting milestones, on track, it must be so tiny, show me!" They put an image on the glowing board of Trent's brain and that is the moment that changed everything. I saw that giant mass, to say it was the size of my fist is not an exaggeration.

The burn of the tears that I'd been holding on to hit the back of my nose and I knew I couldn't keep them in anymore. I broke in that tiny room. No longer leisurely skating

along, I felt the ice crack and I fell into the frigid depths. For me, suddenly becoming a “medical mama” was a shock. I felt like I had been plunged into something that I had no idea how to navigate. It took a while to find my way back to the surface. When I finally did, I felt like a totally different person than the carefree skater who fell in.

I’m telling this story from the perspective of twenty-ish years after that brutal day. I’m sure the years of experiences and struggles in between diagnosis and now will color the way I share it. One thing I can say I’ve learned: if they let you leave after the MRI, that’s usually a good sign.

That day, they didn’t let us leave.

Trent was transferred to the children's hospital, and we had an emergency appointment with the head of neurosurgery. By then, I was pretty numb. I nodded along, and not long after, we were admitted. They believed that Trent had a very large, fast-growing tumor that needed to come out immediately. The doctor laid out all the worst-case scenarios: he might never walk, he might never talk, he might never wake up. His emergency surgery was scheduled for the next morning. They needed another MRI with special locator buttons, so they stuck a bunch of things to his head and put him to sleep again, for the second time.

One of the things that is most salient in my memory of that day, is Trent being so desperately hungry. He was only fourteen months old and was still breastfeeding. He hadn’t eaten in almost twenty-four hours and was becoming hysterical. After the second MRI, they said he could have nothing by mouth until after surgery the next morning. His distress only grew and I could hardly hold him because he was so desperate to nurse, and I was getting pretty damn uncomfortably myself to be honest.

I remember calling my mom to tell her what was going on, and how she dropped everything for her and my dad to get to our home, seven hours away. I remember learning about my mom’s call to my dad. He was golfing at the time and he was so upset that he threw his club so hard it bent. It’s strange what details stick with us.

The next morning was surgery day. That day lives vividly in my memory and flashbacks continue more than twenty years later. We were in pre-op, at Children’s Hospital in Pittsburgh. All of the infant-sized gowns were a peachy pink color. I

remember the surgeon coming in, glancing at Trent, and asking how “she” was doing and thinking, “I really hope you’ve got the right kid’s chart!” Trent was miserable, he had had nothing to eat or drink for about thirty-six hours. He was hungry. He didn’t understand why he couldn’t nurse. He was still dressed in that peach gown. The surgeon came in again for the pre-op talk, and once more referred to him as “she.”

Trent was headbutting me, agitated, trying to nurse. My body agreed with him, which left me feeling physically and emotionally uncomfortable. When it was time, I walked into a long hallway holding him. A nurse took him from my arms, she had to pull him off of me, he was clinging so desperately. She started walking down the hallway with my baby. Trent, who was always such a mama’s boy, wouldn’t have liked this under any circumstances. He started screaming for me, “Mama! Mama!”, over and over, reaching for me while the nurse carried him farther and farther away. They went through a door that closed behind them, but I could still hear him crying for me.

The surgery was long. Six hours went by before they even started closing up. And what they found surprised everyone. In one of those tiny consultation rooms, the surgeon told us, “When we got in there, blood that looked like motor oil started pouring out all over the table.” What they had thought was a solid mass was actually full of blood.

No one seemed particularly interested in figuring out what it was or why it happened. They did an angiogram which was unremarkable. We were told it was “weird” and hopefully wouldn’t happen again. Trent was taken to the PICU, where he slept much longer than anyone expected until his team was getting worried. They loaned me a pump from the NICU so I could keep my milk supply up while he slept. Eventually, they gave him a blood transfusion (we would later learn that he had an undiagnosed bleeding disorder, which may have contributed to the situation).

It was a couple of days before Trent really woke up. They had soft restraints on his arms to keep him from bending them or pulling at his IVs. When he finally opened his eyes, he looked at me and croaked, in his tiny, unused voice, “Mama.” He tried to reach for me, realized he couldn’t move his arms, looked a little confused, and croaked, “Uh-oh.”

Mama and uh-oh ranked up there with his favorite words at that time. Hearing his tiny little voice is when I finally felt like I could breathe again!

While I think of the story that I just told as the moment Trent was diagnosed, it really wasn't. The actual diagnosis came about a year later, casually dropped by an amazing neurosurgeon in Boston.

But I'm getting ahead of myself. We were sent home after about a week in the hospital to therapy, follow-ups, and a million specialists. Going home did not mean going back to normal. Therapy became part of our routine, often six visits a week. Play became therapy. Meals became therapy. Life became therapy.

As Trent grew, it became clear he wasn't going to outgrow his physical challenges. So our goal became function. Close the gap. Nudge him toward typical. Our whole lives bent around appointments, and when we weren't at one, I was researching, learning, hunting for anything that might help. Anything that might move him closer to his peers. I was a mother obsessed.

Helping him be as typical as possible felt like the best way to protect him from the world. It felt like love. The more he could fit in, the easier the world would be for him. Eventually, I realized that I was pushing a star into the circle slot on a plastic shape sorter. The only way to make that star fit would be to break it, to clip off its points. And that was not an option.

He didn't need smoother edges. He was a star, dammit. Loving those sharp edges, and accepting that he was never meant to be a circle, was one more way being Trent's mom was reshaping me... But I'm ahead of myself. Again.

### ***Oh My Gawd, It Has a Name***

We eventually got into a groove with this life and then, our world went off its axis again. On a follow-up MRI about 9 months past his original surgery, the radiologists detected new bleeding in the surgical area. The neurosurgeon in Pittsburgh told us he could go back in, but would likely paralyze Trent in the process, so he obviously wouldn't recommend it. Trent's lovely neurologist mentioned a friend, a neurosurgeon in Boston named Michael Scott. We made an appointment, sent records and MRIs on CDs, and drove from Pittsburgh to Boston to meet him.

Dr. Scott was like a warm hug. Neurosurgeons sometimes earn their reputation for being a little prickly and having less than gentle bedside manners, but Dr. Scott was like a wise grandpa, ready to explain all the things we didn't understand. The surgeon in Pittsburgh had basically told us he had no idea why Trent's brain had bled and that we should just hope it didn't happen again. When Dr. Scott explained that the "popcorn" lesions on the MRI were classic for cavernous malformations, finally giving this beast a name felt like a really big deal.

Dr. Scott told us he could remove the problem lesion, and we wanted it out. We thought that would solve everything: no lesion, no more bleeding. We didn't really get it. We scheduled the surgery, went home, and began the arduous process of fighting our insurance to pay for it. Our local surgeon was in-network and, on paper, "perfectly capable." Except that he wasn't! Only a lunatic would let him operate on their kid after he told us he couldn't do it without paralyzing him! The insurance company went back to the original surgeon and told him that Dr. Scott wanted to do the surgery. Our local surgeon replied, "Well, if he can do it, I can do it, no problem!"

Nope! Big problem. We appealed and appealed again. I was twenty-six, a graduate student, parenting this complicated kid, and now fighting insurance companies. Come on universe! I had no idea what I was doing, but my stubborn nature came in handy and I just refused to give up.

Eventually we got it sorted and went to Boston. We did the pre-op appointments and some sightseeing. I have fond memories of Trent at the aquarium there. We also learned that he had a strange reaction to chloral hydrate. This was a liquid medicine that they gave to babies to help them sleep for tests like MRIs. Most kids wake up floppy and out of sorts, but Trent woke up mad. He was usually such a sweet little guy, so his "wake up mood" was a big departure from his normal personality. After punching his dad for no apparent reason, he delivered what has become a classic line in our family: in his tiny baby voice, "I hit you. I liked it." We cracked up.

My parents came to Boston to help for a couple of days. They didn't even tell us they were coming, they just showed up and quietly did whatever needed doing. They only stayed a short time, but it steadied me in a way I didn't know I needed. It helped calm my soul.

Boston Children's felt different from the moment we arrived. They treated Trent like a little human dude. At our local hospital, we were told to hold him down for procedures. In Boston, they gently but firmly told us they didn't want him to associate his parents with pain. They would handle it. They wanted him to remember us as safe. It was so obvious and so sensible, but it hadn't occurred to me before the nurses in Boston laid it out so plainly.

On the day of surgery, we were in pre-op when Dr. Scott came in to walk us through the plan. While he was talking, someone from finance rushed in, insisting insurance hadn't actually approved the surgery and that we'd need to call it off. Dr. Scott, usually the calm grandpa, turned stern in a heartbeat. He told her we had enough to worry about, that this surgery was happening, and that pre-op was not the place for that conversation. She scurried out of there pretty quick! They gave my little man some grape-flavored medicine that made him sleepy and goofy, and then they took him away.

Besides Dr. Scott, one of the reasons we chose Boston Children's was their "In Operating Room" MRI machine, which was rare at the time. It meant they could confirm the lesion was gone before closing. Of course, the day of Trent's surgery, the machine was down. They closed him up and did a regular MRI afterward.

On the MRI, there was a spot. A tiny speck that might have been nothing or might have been a fragment of the lesion. The young Fellow that Dr. Scott was training thought it was a lesion speck. I felt like I was living in a perverse version of Horton Hears a Who: "A lesion's a lesion, no matter how small." But Dr. Scott believed it was just an artifact and not worth the risk of going back in. So, the speck stayed.

We spent some time in Boston while Trent recovered before heading home. Trent picked up a Boston accent, shouting "oh my gawd" and other Bostonisms that sent us into hysterics. When we finally got the go-ahead to return home, we were so relieved. We almost made it out of Boston without incident, but then came the airport. My husband and I were separated in security, and I had Trent in the stroller with his blanket and diaper bag. He was fussy and in pain, with a compression wrap on his head because of spinal fluid issues, and he couldn't really walk, so the stroller functioned like a wheelchair. The TSA agent insisted he get out. I picked him up, and then the agent grabbed his blanket and tossed it on the conveyor belt. Poor Trent went off. He wailed,

and even through the compression dressing I could see the fluid in his head pulsing. I was an anxious mess! We muddled through security and were so glad when we finally made it home.

### ***The Way She's Wired***

Trent was only two years old when he had that 2nd surgery. He had ups and downs afterward, but things were pretty quiet. Around age three, we learned he had familial CCM, specifically CCM2. They tested my husband and me. I was sure it had to be from my husband, because his family is a hot mess, but alas, I learned that it came from me. I had complicated feelings about that. I was so grateful Trent was alive and here on this earth, and I wouldn't give him up for anything, but the guilt was tough. Later we learned that my dad, sister, and several aunts and uncles also carried the gene. It took my while to get there, but the person I became understands that if the choice was between having my kids exactly as they are, CCM and all, or not having them, it's an easy decision every time.

Accepting that Trent would always be disabled didn't mean we stopped trying to help him grow stronger. It meant helping him become as independent as he could be, because more independence meant more options for his future. We tried everything we could find. Therapies. Specialists. Weeks away for intensive programs. And eventually, adaptive sports entered our orbit. We had no idea how much they would shift the trajectory of our lives. We started out aiming for the moon, but we ended up on Mars, and Mars was awesome.

With all of this going on, we decided that it would be unwise to have more children given all of Trent's challenges. The universe laughed at us, and we were surprised by our daughter Amarisa (Ama) almost exactly nine months after deciding not to have more children. The universe definitely got it right. She brings so much laughter and joy to our lives, and life is never boring with her around. We had Ama's cord blood tested when she was born, so we've known for most of her life that she also has CCM2. Trent adored her from the start (well, most of the time) and from the time she could talk, she has been fiercely protective of him (from everyone but herself).

Ama hasn't had a lot of problems with CCM, but when she was in fourth grade, she fell off the monkey bars at school and a head CT found two lesions, both in her temporal lobe on either side of her brain. The hospital insisted she have an MRI before we left in case it was a tumor. It was frustrating because we knew exactly what they were. Nevertheless, at 2 a.m., an MRI confirmed they were CCMs, and both had bled at some point in the past.

Ama is a unique human. She is incredibly bright, with a love of writing, English, and grammar, but she struggles with executive function, anxiety, and ADHD. She was eventually diagnosed with autism in 2021. Are her struggles related to her CCMs? Would she have these same challenges if she didn't have lesions in her brain? We'll never know. I hate how much she struggles and how hard she is on herself. As a gifted child with disabilities, she is considered twice-exceptional. Twice-exceptional kids often have a hard time. Being gifted, but struggling to perform, can lead to really harsh judgements, both from themselves and everyone else!

Ama's life has also been shaped by being the sibling of someone with a disability. She grew up in therapy offices, and our family trips were usually to her brother's adaptive sports events or for medical care. Trent's illness and disability touched every part of our lives. Ama actually learned to crawl at the Ronald McDonald House in New York City.

Even when the underlying reason for a given trip was for Trent's sports or to see a specialist, we tried so hard to make really special memories with Ama while we were traveling. If we were somewhere for Trent's adaptive track and field, we made sure she got to go to amusement parks and experiences she was excited about. When Trent spent days at an orthotic clinic in Sweden, her dad took her to the Pippi Longstocking museum and everywhere else that felt magical. When we were in New York for one of Trent's programs, we took her to the American Girl store, saw a show she wanted to see, and even braved the hectic M&M store! And still, after all of it, she would say, "Yeah... but it was really all about Bub." And she wasn't wrong. We wouldn't have been there if Trent weren't sick.

Ama grew up seeing up close what this disease can take. She has always lived with the unique tension of knowing she was loved deeply and still feeling secondary; of

knowing why her brother needed extra attention sometimes, yet resenting it anyway. She worried about her brother, feared for herself, and felt pushed to the side for not being sick enough, but also felt “like a piece of shit” for feeling that way.

At eighteen now, Ama is a senior in high school. She is homeschooled but takes her academic classes at our local community college. She’ll likely graduate high school with her Associate Degree, an impressive feat. She loves theater and is an amazing singer. She’s probably not ready to go away to college, which is my current source of stress. How do I know if I’m holding her back because of my own fears or if she genuinely needs more time? She’s so sensitive to failure that sending her off too soon feels like a recipe for disaster. I’d like to believe she’ll rise to the occasion and prove us all wrong, but I’m not sure that she will.

My funny, lovable Ama has always been a word person. She talked early, read full novels in first grade, and was tackling college texts by sixth. She has been editing my writing since she was eleven. She loves to read, to write, to think deeply about things, and the excitement of a good debate.

Unfortunately, her two larger lesions sit in her temporal lobe. The temporal lobe is the part of the brain that allows us to understand and use language. It helps us attach meaning to words, retrieve the right word when speaking, read and spell, and connect sounds to ideas. Different areas work together to help us name objects, follow conversations, and make sense of both written and spoken language. When that system is disrupted, language can become confusing or frustrating, even when intelligence and thought are completely intact. Ama understands all of this. When you are wired the way she is, you end up connecting the dots, even when the picture they make is terrifying.

For her, the fear is not abstract. It is not just about being sick someday. It is about losing her words. Her voice. The way she makes sense of the world and connects to it. The possibility of losing language feels like losing a huge part of herself. Carrying the same diagnosis as her brother, though without the same severity, has given Ama a perspective few children have. The fear has lived quietly in the background of her childhood, even as the medical hits kept coming for Trent.

### ***Third Time's the Charm***

When Trent was in third grade, he had his first “ice pick” migraines at school. They were brief, but debilitating. The nurse sent him back to class, but when I finally saw him after school, I was worried. That evening, we had tickets to *The Nutcracker*, and he really wanted to go. My intuition was pinging, but I figured I could watch him just as easily at the ballet as I could at home, so we got bundled up and went. By the time the show was over, I was certain something wasn't right.

One of the many challenges of raising a child with this condition is that it's often impossible to know whether something is a normal childhood illness, a typical part of development, or something truly serious. In the early years, that uncertainty led to a lot of emergency room visits. As Trent got older, I became better at figuring out what warranted an ER trip and what I could safely monitor at home. This didn't feel like a watch at home situation.

That night, with my husband traveling, I took Ama to a neighbor's house and headed to the emergency room with Trent. A couple of residents came in and ran a bunch of neuro tests, “touch my finger, touch your nose” and “follow the light.” And then they had him wiggle his toes. He couldn't move his right big toe at all. He had previously been able to wiggle it, at least a little bit, but in the ER it was totally paralyzed. When I saw that, I had no doubt something was wrong. Watching him trying so hard to wiggle that toe—the concentration on his face as he tried and tried and it wouldn't move—really shook me.

We waited a long time in a holding space for an MRI where we watched the movie, *Elf*, over and over again. I waited there during the scan, so I got bonus time to watch *Elf*. I can't watch that movie without thinking of that night in the hospital. It's not a hard memory really, Trent and I hung out and snuggled and laughed as we waited. Later, we learned that he had suffered another significant bleed in the same area. That tiny speck had grown again, and now it was bleeding.

The doctors kept him in the hospital for almost a week to ensure that the lesion stopped bleeding. On the morning that he was discharged, I was supposed to be reading a holiday book for Ama's preschool party. I really didn't want to miss it. I

dropped Trent off at home with his dad, bought *Llama Llama Holiday Drama* from our local Kmart and went to read to preschoolers. I remember being so profoundly exhausted. But when I saw that Ama was so happy that I was there, my exhaustion no longer mattered. And I remember other moms, the moms whose kids were healthy, fussing about all the holiday stress and thinking how lucky they were.

After Trent's discharge, we met with three surgeons. Dr. Scott recommended removing the cavernous malformation. The original Pittsburgh surgeon said to leave it alone, again. I was so torn with such contradictory recommendations that I made an appointment with a third vascular surgeon. She helped us make a plan: one more bleed would be the threshold, then we would operate.

When Trent was twelve, we moved to the suburbs of Philadelphia. Not long after, a routine follow-up MRI showed new bleeding. Shortly after that, Trent had a seizure in the car while I was driving. It was terrifying, and I knew that it was clearly time. The plan we had settled on had bought him four more years for him to get older, stronger and for his brain to grow so that surgery would hopefully be a little bit easier. Before we made the final decision, we consulted Dr. Awad in Chicago, Dr. Storm in Philadelphia, and Dr. Scott in Boston. Everyone agreed surgery was necessary which made the decision a lot easier. I highly recommend a second opinion when making these decisions, and clearly a third can be a huge help too!

This surgery was harder because Trent fully understood what was happening. I will never forget snuggling with him as I was tucking him in one night when he asked me, "Mom, what if I die?" I had to hold it together because I needed to reassure him and falling apart wasn't going to do that. The back of my nose burned as I held back the tears. I told him that he had the very best team on his side and that we trusted his doctors, and we were confident that they had it all under control. And I didn't cry until I was safely out of earshot.

On one of our many talks around this time— about how to handle the big feelings he was having— I told Trent that it was okay to feel upset, to get down in the mud, but that he couldn't live there. He had to get up, clean off, and carry on, because what other choice was there? This pep talk really resonated with him, so we talked about getting out of the mud a lot over those days, and still do sometimes when he gets down.

Trent's surgery was scheduled for right after the new year. It turns out when you're having brain surgery right after Christmas you can have pretty much anything you want from Santa, so Trent got a pretty sweet 3D printer that year. He was supposed to go on an adaptive ski trip as his gift, but that was out for obvious reasons. Dr. Storm did the surgery because traveling for surgery and leaving Ama home was just too complicated. He said he followed the existing surgical path and plucked the CCM out like a cherry. All three of Trent's brain surgeries had been on this same stubborn lesion, which is unusual. Luckily, this time Dr. Storm felt confident it was gone. It took us years to finally believe that it was really gone for good.

By the time it was removed it was much larger than a speck, but it brought us full circle to Horton: "A lesion's a lesion, no matter how small." Even the tiniest things can change the course of a life. What started out as a tiny abnormal cell in Trent's brain grew into a lesion that shaped the course of his childhood and changed all of our lives.

Like all children, Trent really wanted to belong to something. He tried typical sports, and while he could play soccer, he couldn't really keep up with his peers. As he got older, they weren't kind about it. That part was hard. He was such an athletic kid, but he didn't have an outlet for it. Adaptive sports entered our world as a way to meet that need for Trent. I didn't understand then how deeply his foray into adaptive sports would shape my own becoming. I thought we were just signing up for running. Wasn't I just precious?

Trent started competing with other kids with disabilities when he was just seven. After his first Junior Nationals, he was hooked. Trent was a runner. Anytime there was open space, he would barrel through it at top speed, crashing into whatever stood at the end to stop him. Running was actually easier for him than walking, because his weaker foot flung upward with the momentum, and he tripped less. As he grew, running got harder. But he got stronger and broader, and he grew into a talented thrower. Eventually, finding his love for the discus.

He had such an amazing time at his first big meet that he asked if we could start a local team to share adaptive sports with other kids. I casually agreed, "sure, why not?", and that simple conversation changed everything. I became the head coach, learned all I could about coaching, and the nuances of para sport. Our team has grown significantly and expanded outside of track to include swimming. Over the years, Trent competed at

Junior Nationals every year. He specialized in discus throwing and eventually qualified to compete at Para Nationals. Beyond competing, he fiercely advocated for the inclusion of disabled athletes in our state's high school track and field organization, and now he actively coaches the next generation of athletes.

I have been head coach for our adaptive Track, Field and Swim team through the Pennsylvania Center for Adaptive Sports for about seven hundred and fifty years . . . . Well, it feels like that sometimes, but really, it's been about fourteen years. What I have learned in those years, well, it feels like seven hundred and fifty years' worth of stuff! Adaptive swim and track rules, the classification system, how to support kids with all sorts of disabilities and then a bunch of other ways because you have to be creative and willing to think about things from all sorts of angles. But man, when it clicks for these kids, it is the most magical experience! And these kids are seriously the coolest humans! I feel so lucky that I get to be a part of their lives.

### ***A Little Shabby, A Lot Loved***

I often joke that the nineties sitcoms didn't prepare me for my motherhood journey. *Who's the Boss* and *Family Ties* had twenty minutes of hilarious shenanigans, all wrapped up in a neat little bow by the end of the show. Everything was always so easy, even when things were hard, it always worked out in the end. As a mom, it was always the decisions that I found particularly difficult. Those sitcom moms never had to make decisions that would tear them apart. I would agonize over whether or not I was doing the right thing. Would the new program I was pushing the school to try out make things better or worse? And how would I even know? What if the seizure meds made things worse or didn't work? We always avoided ADHD medicine because one doctor said to never give it to Trent when he was little, but others said it was probably fine. What if Trent could have been more successful in school with the meds? No decision felt easy, and I was chronically exhausted by the mental weight of it all.

I like to say that I'm good at compartmentalizing. I have all these little boxes and trunks scattered around my mind, and I shove things into them when I can't deal with them at that moment. Sometimes I stack boxes on top to keep those stubborn thoughts from getting any ideas about popping out at an inopportune time. As a psychologist, I'd tell you that sometimes you should sit with your thoughts and feel your feelings, but

here's the thing . . . I don't want to. Is this healthy coping? Debatable. But technically, it *is* coping, healthy or otherwise, and I've got to get through the day.

I had a therapist encourage me to unpack some of this stuff that I had tucked away in boxes and trunks. I spent the time between sessions thinking about that, contemplating whether it made sense. I got to thinking about PTSD. In the field of psychology, we really started to understand PTSD by working with soldiers when they came home from war and were struggling. It's not uncommon for an accident survivor or a crime victim to develop PTSD related to a specific event. Something happened. They survived it. The event ended, but the trauma stayed.

Medical PTSD is often a little different. Sometimes it stems from an incident that has since been resolved, like a surgery from which you have physically recovered. But often, the trauma itself isn't time-bounded. It doesn't live neatly in the past. It hits you over and over, and you wake up every day not knowing if this is the day it will hit again.

There's always another lesion, another scary symptom that might be totally normal or might be a brain bleed. There are always bodily sensations to interpret, nefarious or benign? And for a parent with CCM, who has kids with CCM, there is always the worry about their health and their futures, tangled up with the fear of maybe not being there because of your own CCMs. You wouldn't tell a soldier to process their trauma while they're still in combat. You wait until they're safe, before that work begins. Living with CCM feels like you never quite leave the battlefield. I know in my head that unpacking this shit and feeling those feelings needs to be done at some point, but I really don't understand when I'm supposed to do it.

While I haven't really coped with the trauma, I *have* had to work through the grief. I've struggled with loneliness, because people don't know what to say to a mom when her kid is sick. Because Trent had a lot of behavior problems as a little guy, that made it hard to take him out. The few times I tried, the friends we hung out with never invited us again. And I get it, but it still sucks. We were constantly running to therapy and appointments, and when you say "no, we can't go" enough times, people just stop asking. It was a lot of lonely years when the kids were small.

I've felt guilt, like I didn't do enough, didn't know enough, agreed to things I shouldn't have, and didn't agree to things I should have. I felt guilty for not understanding everything about CCM when even the amazing scientists still don't fully understand it. I felt scared, when he hit his head, or got a headache, when my daughter was crawling in a strange way, or when she struggled to follow rules at school. I felt sad, honestly, so sad and broken, when Trent couldn't keep up with his classmates, when he couldn't do something he wanted to because of his disability, when he started losing his "I can do anything" attitude and replaced it with "I can't do that" more and more often.

The grief was particularly hard because it was layered. While I grieved the life that I thought Trent would have and the added challenges that his life would now hold, I also felt intensely that I wasn't *allowed* to feel that way. I felt like I was supposed to be grateful and positive, making the best of this life even when it felt impossible. When you've been through such horrible, scary things and your kid is still here, it feels like you are only permitted to be grateful because so many kids aren't. You aren't allowed to be upset about the bad stuff. "Toxic positivity" creates this impossible standard. While I usually do focus on gratitude, I sometimes have to remind myself: it's okay to be sad or mad that our lives, our plans, our futures got totally turned on their heads.

And then there is my own complicated relationship with this gene. As a mother with CCM, knowing that I, too, could get very sick, and that I wouldn't be able to take care of my sick kids, is terrifying. The thought of losing the ability to fight for them is probably my greatest source of anxiety. It feels like it always lives just under the surface all of the time.

Overall, I haven't had any huge CCM issues in my own body. I do have some lesions in pretty difficult locations that we're keeping a close eye on. I have two lesions in my thoracic spine and one in my brainstem. And I have lots of tiny "baby" lesions all over my brain. The trouble with the baby lesions is that they leak tiny amounts of blood. While, at least at this size they're unlikely to cause any major problems, the cumulative effect of that leaking blood can do a number on a person's mental prowess. I feel less sharp, word finding takes longer than it used to, and I have had a headache for literally eight years. Every day, I wake up with it, I go to bed with it. It is my constant companion

and makes everything harder. It's a really crappy companion to be honest and I would desperately like to unfriend it.

The other issue with familial CCM is that we will develop more lesions over time. There's always more to worry about and the future feels so uncertain for myself and my kids. The status quo doesn't stay put, there's another bleed or a new lesion or new symptom, there is always something new and exciting to worry about!

When Trent was small, I took solace in the poem "Welcome to Holland" after his diagnosis. If you're not familiar with it, it's a lovely piece about planning and expecting a trip to Italy, only to find that the plane lands in Holland. Holland isn't Italy, but it's still pleasant, so you find beauty in the journey that you're on.

But twenty-two years into this, I can say for sure that this life isn't a trip to Italy *or* Holland. It's more like a cancelled flight when you're on a layover in an unfamiliar, not necessarily attractive, city. It's a place where they don't speak your native tongue. You're stuck in a place that you didn't choose. You have no idea how long you'll be there. You don't know how to communicate with the experts to get your questions answered. It's frustrating, scary and lonely, and then, while you're waiting, you get accosted by the fiercest love you will experience, and it changes you down to the marrow of your bones.

That fiery love is what keeps you going. Learning to fight with schools that write up Individual Education Plans (IEPs) and then ignore them. You end up becoming an advocate on every front, every fucking front, and you don't get a break.

You learn the ins and outs of IEPs and 504 plans, you learn about adaptive sports and opportunities to help your child feel part of a team, to feel normal. You learn about therapy, early intervention, preschool services, school-based services, mental health supports, behavioral supports, medications to treat all of the stuff, ADHD, seizures, meltdowns. Then there's insurance and Medicaid, and vocational rehab, and transition to adult services. You push and you push and you push for everything that your children need and you don't stop. You can't.

And then someone says, "You're so strong, I don't know how you do it," and you're like: "I do it because I don't have any other fucking choice, Nancy." I do it because, there

is so much love for these humans, and so much sadness in seeing them struggle. And if I can do anything, anything, to make life a little easier, then that's what I'm going to do. It's hard. Honestly, sometimes it's devastating, but this fierce, protective love you have is a driving force like an avalanche. It's an overwhelming, unstoppable power.

And this, this is where and how you become. You don't realize that it's happening, but you grow and change. Your hair has been loved off, you get shabby and loose in the joints and you develop this grittiness and fire that you can only get from going through the storm. One of my favorite quotes is "once the storm is over, you won't remember how you made it through, how you managed to survive. You won't even be sure, whether the storm is really over. But one thing is certain. When you come out of the storm, you won't be the same person who walked in. That's what this storm's all about." — Haruki Murakami. I don't know what kind of Mother I would be without the journey that CCM has taken us on. But I feel pretty confident she wouldn't be the badass surviving this storm turned me into.

Anyway . . . this is why I compartmentalize. It's either that or scream into the void, and let's be real, that would just make my head hurt worse. After traveling through the storm that is CCM, the journey, the love, the life we get to have together, as much as the bad stuff sucks, this life we get to live? It's still worth every headache.



# Blackberries & Blue Butterflies

By: K.C. Eames

Time softens the edge of things.

I have replayed that Friday morning in my head many times. I made myself a huge salad and dumped a can of tuna on top, for extra protein. It sounds so irrelevant, but I remember it clearly. I remember thinking the tuna didn't taste great. I kept eating it anyway. It was a huge salad. I felt a tiny bit nauseous after finishing it. Not a fan of canned tuna anymore.

I was at my desk working in my room, in Bozeman, Montana. A strange headache started to creep up, it started all over my scalp, then converged around the left side of my face: my eye socket, left nostril, left cheekbone toward my ear. The left side of my face was really uncomfortable and my skin felt sensitive. I was wearing a beanie and thought maybe it was too snug on my scalp, or maybe the knit material was irritating it. I took it off. That wasn't it.

Maybe it was just a weird migraine. I've had a handful of migraines before, it felt like something I could work through, or wait out, or maybe sleep off. It didn't feel like the kind of thing that changes your life.

A little after 12 PM, I put on an "out of office" away message so I could step away from my desk because it had become too hard to focus. I laid down to sleep it off, but by 5 PM, nothing had changed. I was so uncomfortable and exhausted from the pain that I dragged myself to my car and drove to urgent care.

As the nurse shuttled me into a room, she instructed the staff to keep all the lights off for me, assuming the migraine would make me sensitive to light. I wasn't, though. Light wasn't bothering me. All I could do was hold my face in my hands, even though it wasn't alleviating any of the pain.

They gave me a shot in my right butt cheek, and some anti-nausea medication. I waited 15 minutes for it to kick in, and when she came back, I reported my headache went from a 10 down to an 8.5 in pain. Improvement, I guess.

I climbed back into the car and rested my head on the steering wheel to gather strength and focus to drive home. I crawled straight into bed.

By Friday night, the headache had subsided, but the nausea had intensified and taken its place. We had just moved into a new place, so our mattress was on the floor. I willed myself up, and crawled into the bathroom. I immediately started throwing up. I threw up my whole salad. I threw up 13 times, I kept count. I would fall asleep for half an hour, wake up, and within a couple minutes throw up again, then pass out. I worked my way through every type of fluid: Sprite, Pedialyte, Gatorade. Every time I drank something, even plain water, I threw it up within a few seconds.

I had made myself a little rat's nest on the floor, I curled up on the bathroom mats and pulled the towels off the rack to use as blankets. By 5 AM my boyfriend came in and told me I hadn't thrown up in a while, so I should come back to bed. It did feel like the storm had passed, so I crawled back into bed and slept.

Late Saturday morning, I opened my eyes, and the room was spinning. I tried to focus my vision on something still, and I saw double. I closed my eyes for reprieve. Every time I opened my eyes, the ceiling swirled. The left side of my face felt cool and tingly. My left index finger and thumb were tingly. My left eyeball was numb. The inside of my mouth felt like it was smothered in Icy Hot or menthol.

I was ready to try getting out of bed so I could brush my teeth, and the movement was enough to make me throw up again. I climbed right back into bed for more sleep. Around 7 PM Saturday night, I rallied my energy to take a shower, and as soon as I got out of the shower, I threw up again.

I was starting to get worried, not a lot, but maybe this was more than a migraine?

At this point, I wasn't in a state to drive. I slid down the stairs leaning against the wall, holding my face in my hands. My boyfriend brought me my shoes and drove me to the ER.

As soon as I walked in, they poured me into a wheelchair and gave me a plastic bag to throw up in. I was seen quickly, they wheeled me in for a CT and then an MRI. I waited, drifting in and out of sleep in the hospital bed.

The doctor finally came in to say she didn't see anything unusual in my scans. She was ready to discharge me but wanted to make sure I could walk independently before doing so. One nurse stood by my side while I walked toward the other nurse - I was intent and focused, trying to pass so I could be released and go home.

I felt like I got from point A to point B, so I was sure I had.

"Did I pass?!"

Both of the nurses exchanged glances, and one of them said, "I wouldn't call that passing."

The doctor said, "You're not neurologically stable."

I remember her quizzically looking down at me doing her vision test, moving her fingers in front of my face as I confirmed I saw twice as many as she was holding up. She knew something was wrong, but she didn't know what. It was Saturday night, and the neurologist wouldn't be there until Monday - and it didn't feel like I had that kind of time.

She said she might send me to Billings. I told her I didn't want to go to Billings, so she said she'd call around and see what kind of information she could get. She contacted Utah Medicine, to have the neurologists there review my scans.

When she came back in, I remember so clearly looking up to see her face peering down at me when she said, with a new kind of certainty in her voice, "There is an abnormal cluster of blood vessels in your brainstem. We need to transport you to Utah."

Holy shit. OK.

It was only at that moment that I felt scared.

It's a tumor. It's cancer. I'm dying.

Those were my thoughts.

The doctor spent the next seven hours trying to secure an air ambulance. There was an active blizzard, so the med plane kept getting delayed and stalled. Finally, a plane came through around 1 PM.

I waved goodbye to my boyfriend as they loaded me onto an ambulance to take me to the airport. I remember looking at his face as the ambulance doors closed and wondering if it was the last time I'd ever see him. I had nothing but the clothes I was wearing, my purse, and my phone as I was whisked out of state. I thought about my computer bag at home. Irrelevant. It's amazing how quickly everything that you think is important in life deprioritizes when health forces its way into center focus.

Lying in the gurney in the ambulance on the way to the med plane, I thought about my life, and I asked myself if I'd lived it the way I wanted, if I had any regrets. I had lived a wonderful life. I traveled, played, loved. I had no regrets. There was a peace and calmness I didn't expect to feel, and a resolve that if this is how I was going to die, it was ok. Most of my fear of death lives in the unknown.

The EMT asked me if she could pray for me. I nodded. She put her hand on mine, and prayed out loud for my comfort, safety, and health. It made me cry.

A team transferred me from one gurney to another as the blizzard howled around us, and they loaded me onto the med plane. A private plane just for me! The high life.

It was an hour and a half flight, I was comfortable at this point, no longer in pain or discomfort. My emotions weren't intense. I was just there, existing, waiting.

On the next ambulance from the SLC airport to Utah ER, I started to cry, probably more from exhaustion than anything else. Quiet, slow tears streamed down my face. One EMT with short, strawberry blonde hair saw me crying and put his hand on me and said, "One day at a time."

They wheeled me into the ER, and I saw my dad standing in the hallway as they rolled me through. My mom was sitting in a chair nearby. My parents had beaten the med plane to SLC, from San Francisco. It was wonderful to see them.

The first night in the ER was absolutely the worst. The protocol in Neuro ICU is to wake you up every hour on the hour and ask you the same questions:

- What is your name?
- What is today's date?
- Where are we?

- Why are you here?

I wasn't allowed to sleep flat because they wanted to minimize swelling and inflammation in my brain, so they angled the bed at 30°. I slid down, my feet pressed against the bed frame. I wasn't allowed to consume anything, not even water, so they gave me a cubed sponge on a stick so I could wipe the inside of my mouth. This is literally torture.

Most nights I just stared at the ceiling through broken sleep. I never once turned on the TV or a podcast to pass the time. My brain did not want any input, it wanted peace and silence.

One neurologist explained that surgery wasn't an option in the brain stem, because "it's in a very important part of the brain." I laughed inside at that statement. What part of the brain isn't important?

So, what can be done about it? One of the doctors said, "Just live your life." How can he say that?

The week blurred together in the hospital. During those six days, I must have received care from over 100 people: EMTs, nurses, neurologists, phlebotomists, physical and occupational therapists, a pharmacist, a dietician.

Two occupational therapists arrived together. They were young and both had bubbly and vibrant energy, a taller redhead and a shorter brunette. We walked around the halls and they evaluated my balance in the PT room, standing on various objects. Their auras felt like two little butterflies fluttering around me. They praised my neuroplasticity and my capabilities, and gave me confidence that my vision, stability, and balance would go back to normal.

I had no appetite, except for pineapple.

Being quite independent by nature, I had already received a few warnings for ignoring the nurses' instructions to use the call button so they could accompany me to the bathroom. After a few days, I was finally granted permission to use the restroom on my own. My vision started to improve. It was best in the morning and gave me hope that I was recovering, but then it deteriorated each day with fatigue.

I was released from the hospital and relocated to a hotel in Salt Lake City that night. On the drive over, I couldn't keep my eyes open fully. Everything seemed so fast-moving, blurry, exhausting to track. It felt like when you get your pupils dilated, everything is so bright and uncomfortable to look at. I requested a room as close to the lobby as possible, to minimize any extra walking.

I couldn't wait to shower for the first time and wash my hair after six days marinating in a hospital bed. The steaming hot temperature I normally love was too intense, so I showered lukewarm. I had to move very slowly, I couldn't rotate, bend over, or turn my head much at all. My brain wanted stillness.

The next morning, we stopped at Jamba Juice for a peanut butter smoothie, the only thing that sounded good to me. It was cold, sweet, and delicious.

I immediately started to hiccup.

They were intense hiccups that quickly became exhausting. I tried every trick to make them stop: holding my breath, drinking water, plugging my nose. I learned through trial and error that if I drank warm water and took very slow, deep, focused breaths, I could calm my nervous system down to the lowest level and the hiccups would subside.

But as soon as I activated anything, like getting up to go to the bathroom, the hiccups started again. They lasted for hours at a time, to the point my abs ached. When I woke up in the middle of the night, bladder full, I tried so hard to will myself back to sleep because as soon as I got up to pee, the hiccups would start again and I wouldn't be able to sleep for another couple hours.

I started to fear I'd have hiccups forever, that I wouldn't be able to hold a job, that I couldn't have a normal conversation without hiccupping. I didn't realize it then, but this was my first meeting with the psychological monster that accompanies medical trauma. At the store, picking up some groceries, I went to ask a clerk for something but my hiccups were so intense, I couldn't ask her - I was embarrassed I'd croak in the middle of my sentence, and I started to feel so isolated and fearful of this new life after stroke. A prescription relaxant relieved my hiccups. Still, I worried it was a deeper defect from my hemorrhage, and that as soon as I stopped taking it, they would come back.

I had lost 10% of my weight in a week's time. I had no appetite. Andrey brought home an assortment of foods to see if anything sounded good, but nothing did, except for the tub of pineapple. I started to worry I would never be hungry again.

My brother flew into Bozeman to drive me back to spend time recovering at my parents' house. Back in my childhood bedroom, I felt calm and at ease, and our family cat, Lewis, became a powerful source of therapy for me.

The physical symptoms improved gradually over the course of four weeks. It was hard to focus on screens, but I got back to work catching up on recorded meetings, finding adaptive ways to work like listening and dictating rather than looking and typing. It felt good to be productive, to be able to use the part of my brain that wasn't malfunctioning.

I couldn't focus on fast-moving objects, so I couldn't drive or bike, but I took slow walks accompanied by my parents or my brother. I missed biking, so my family suggested and helped me acquire a bike stand from Goodwill that converted my dad's mountain bike into a stationary bike. I set it up on the back deck, positioned my iPad in front with a spin cycle class on YouTube, and pedaled away for a couple of hours every day. It felt good to feel my lungs burning, to feel my muscles strengthen, to feel my body in movement.

As the physical symptoms ramped down, the emotional effects tagged in. And they hit hard and heavy.

As I reflected on my new circumstances, my world shrank. My future, which had always felt like an endless horizon, now felt like a big concrete wall had been put up in front of it. My life now felt like a dead end.

I feel like I had faced my worst fear, death, but I was burdened with completely new fears that felt far worse: living a life I did not want to live, fearful, anxious, and restricted.

I can never travel internationally again. A bleed could happen on the plane, or in another country. I could never go backpacking into the woods with my brother, in case a bleed happened in a remote wilderness far from a hospital. Could I even live in Montana anymore, where they didn't have sufficient neurological expertise to handle my condition if something happened again?

I took for granted I'd always be employable with my college degree and CPA license. I remember my uncle's words: "You always have your brain." But what if I don't?

I have always feared my parents aging. Having to care for them and watching their decline is a heartbreak I dread. But what if this happens again? What if I become a vegetable, and my aging parents have to care for me? That one, that fear, turned me into a puddle of deep, overwhelming misery, anxiety I didn't know how to process. It felt like a heavy pressure in my chest, and a spiraling of anxious thoughts. It was debilitating.

I didn't know what version of myself I was going to be on the other side of this. What if my personality changes? What if I become depressed? What if I become something that my friends and family don't like? Will I just go back to being myself with this new experience, or will it fundamentally change who I am, for the worse? Will I be able to pull myself out of this?

None of this showed up on the outside. When I saw friends or family members, they'd say, "You look great!" I know they were being positive and encouraging, but what they couldn't see was this huge, all-consuming thought that hadn't resolved after the blood resorbed, and the vision stabilized, and I could walk again.

How do I get rid of the weight of knowing I have this little blackberry in my brain forever? And it could bleed again at any moment, and next time it could be worse and the symptoms irreversible. And there's nothing anyone can do about it.

I crossed a threshold I didn't ask to cross. It felt like a two-way mirror where I'm on this side looking back at everybody else and their life seems so light and simple and trivial. I don't mean to put that down. It's just a different perspective. I don't like having this new perspective because it feels lonely and heavy. What I really want is for everyone to be on the same side of the threshold as me. I feel alone on this side of the glass looking through.

During this time, I found myself seeking more connection to people in my life. When I was in the hospital, human connection felt like the only thing keeping me grounded when I felt like I was in a nightmare. I texted and called friends to catch up and talk about my experience.

When texting with a friend and sharing the intensity of my emotions, he texted back, “You’re just going through a little metamorphosis,” with a blue butterfly emoji.

I received care packages from friends, and opened one to find a coffee mug that said, “One day at a time...”

Another friend, who had suffered from a stroke himself a decade earlier, told me he was grateful for what came from his experience. I couldn’t fathom those words at that point. How could one ever feel that way? What is there to be grateful for?

These perspectives eventually helped pull me back to the other side of the threshold as everyone else.

Fast forward a few months: a handful of EMDR therapy sessions helped take the edge off, and my whole experience has started to feel like it happened in a past life.

I’m in downtown Bozeman, at my favorite shop, Heydey, when I came across this little jewelry dish. It was blue and in the shape of a butterfly. In the middle of the dish, it read:

“Just when the caterpillar thought its world was ending... it turned into a butterfly.”

Nothing has ever spoken to me more. I bought it.

Over the past two years since my bleed, my world has opened up again. I’ve traveled internationally several times. I’ve backpacked and camped. I’m happily still living in Bozeman. Not only am I back to baseline, I started to step out into the public arena.

My desire to connect with others has driven me to take on new challenges I never would have previously considered. I started training for public speaking and presented on stages at work conferences, in webinars, and in podcasts. I started improv classes, an activity that previously made me cringe at the thought of it. My social network has expanded exponentially. My life has never been fuller.

Logically, I am fully aware of my circumstances. Nothing has changed. That blackberry is still there.

But the questions and statements in my mind have softened, twisting from half empty to half full.

I used to think, “I’ve always been so attentive to my health and fitness, why did this happen to me?”

Now I think, “My health and fitness may very well have held off a bleed for 35 years. And it’s possible I recovered so well because of my focus on health and fitness. So, keep at it.”

I used to think, “It could happen again at any time.”

Now I think, “I’ll cross that bridge when I get there.”

Instead of thinking, “Next time it could be worse.”

Now I think, “I got through the first one, I’ll get through the next one.”

It’s not all rainbows and butterflies. I still sometimes feel a twisted mix of emotions that I haven’t fully worked through. I’ve had the Cavernoma Support Group Zoom meetings on my calendar for almost two years and still haven’t brought myself to attend a single one.

When I learned of the Alliance’s family picnic, I refused my family’s invitation to accompany me because I thought I might make the hour drive down and not be able to get out of the car, and I didn’t want to waste their time.

When I learn of other people’s condition, those with permanent deficits and daily physical reminders, or those who have lost loved ones to this disorder, my body gets hot all over and I feel an overwhelming, sickening sense of fear and guilt. At the same time, I feel gratitude that I recovered fully, but that gratitude is conditionally attached to more guilt. It’s a complicated emotional evolution that is still in progress.

I am no more special, I am no more strong, I am no more resilient than any other human being for having gone through something like this. I believe humans are built this way. Our ability to adapt and overcome and persevere is stunning.

I do daydream about what it would feel like to have a magic laser that could just zap this little blackberry away, to be free of the baggage of it. But the thought of it doesn’t hold me back from living.

I still want it gone. I just don’t need it gone to live.

And at this point in my healing, I understand what the doctor meant when he said to just live my life. I understand what my friend meant about being grateful for what came of his life after his stroke.

Time has a way of softening things. One day at a time. That's the only way to live with a blackberry in your brain.



My first night in the hospital



My first overseas/international trip after my bleed which was a significant milestone and overcoming for me. (with my brother)

## CCM1

### **The Wife, The Mom, The Mimi, The Aunt, and the Great Aunt**

#### **I am in this, too**

By: Genise Oldenburg

#### ***Life Before CCM***

Our lives before CCM were far from perfect, but we lived quite a typical Midwest family lifestyle. I met my husband soon after moving out on my own. I had grown up in the small rural town of Coleman, Michigan and he in the nearby city of Saginaw. He loved the serenity of the rural life, so after we married in 1990, we built our home just outside of Coleman. We commuted for work and once we had children, we commuted them to parochial school within thirty minutes of our home. We and our three children (born 1991, 1993, and 2001) enjoyed many years of the bliss of just good old normal middle-class life: themed birthday parties for the baby through toddler years; just some cake and ice cream with family for birthdays as they grew older. We then moved into the phases of friends for sleepovers and pool parties, homecoming courts, parades, spirit weeks, dances, and proms. We experienced the usual sports related ailments, bumps, and bruises along the way but overall, fewer than two handfuls of incidents between three children. And all without lasting residuals. Life was overall calm and happy. When we reached the phase of having two young adults and the third one in high school, my husband and I were feeling pretty accomplished and successful. We did it. We had raised three healthy great kids.

By 2014, we had added two sons-in-law to our happy family. And by the summer of 2015 my husband and I were just a few weeks away from entering our next season of life: we would be grandparents in late July! While I looked forward to deciding on what my grandparent name would be, my husband said that the name “grandpa” would do him just fine. I was over the moon looking forward to all of the future shopping, spoiling,

babysitting, and smooching that I could get into my schedule. And there was no way this baby would be lacking in the cuteness department, either; for our daughter was a blue-eyed blonde and our son-in-law sported beautiful dark hair and the deepest brown eyes. I was beyond excited and totally ready to give up my hair color and go all gray like a grandma. Life was great. Just a few weeks to go! At the time, it seemed like life just couldn't get any better than that 2015 Memorial Day weekend when we were all together laughing and enjoying our growing family. Everyone was healthy and happy; until we weren't. In June of 2015, our lives would be forever changed.

### ***The Signs Were There***

As my middle child has said, "It all started with a nap." And technically, it did. I will never forget the details of those first hours. The day went spinning soon after I got an odd call from her. She was disoriented and, at first, I thought that she had just slept deeply during an afternoon nap. After all, she was eight months pregnant. I soon realized that it was much more.

She had sent me a photo just before calling me, but it did not come through for several minutes due to my poor cellular service while at home. During our conversation about her waking from a nap and finding herself on the floor beside her bed, a ping sounded from my iPad. As I looked at the photo that she had sent me, I slowly processed what I was looking at as my panic rose. Her face looked as though she had been beaten. One eye was severely bruised and swollen and I could see trauma marks over her whole face: cuts, scrapes, and gashes.

I tried hard to stay calm, while asking her a few questions to decipher what she was saying to me, and somehow simultaneously sending a text message to her husband that there was an emergency. At one point while talking to her, I interjected with, "When did you take the photo from your bathroom?" She did not know what I was talking about. She kept repeatedly saying that she just woke up and was on the floor beside her bed. I knew then that I needed to keep her on the phone while I drove to her, but if at any point she stopped responding I would call 911. Something was very wrong. But what and why?

Her husband was able to get to the hospital fairly soon after we had arrived. The visit to the hospital confirmed likely seizure activity. Tests and scans showed nothing damaging and also - the baby was fine. Thank you, Lord.

Over the next weeks with no answers, but with close monitoring of family (staying with our daughter twenty-four hours a day), we all did our best to keep her calm. We had trips to the hospital as the result of three more seizures. The baby was monitored each time. All was still overall “okay.” But what did “okay” really mean?

### ***The Diagnosis***

Our beautifully perfect granddaughter was born in late July of 2015, as expected, and all went smoothly for the delivery. Praise God. Immediately after the birth, our daughter and her husband requested a referral to the University of Michigan hospital in Ann Arbor. It was at the epilepsy center there that she received an MRI and we received the phone call at 5:20pm on a Friday with the diagnosis of Cerebral Cavernous Malformation (CCM). The hospital also informed my daughter that they would gladly accept her as a patient, however they were not deeply knowledgeable of this very rare condition of blood vessel cluster lesions in the brain.

In less than an hour, both of my daughters and I had done quite a bit of speedy research. While my daughters had found a lot of information online, my efforts were not as fruitful. Owning a home health-care business, I had reached out to my RN staff as well as to classmates with medical degrees. All had the same reply: “I am so sorry to hear this. I can break down the terminology in the same way that you have; but I have never heard of that condition before.” My heart sank a bit more with each response. I was finding it harder to breathe with each reply. My baby girl had a condition that was so rare no one had heard of it. What were we going to do? I prayed. Hard. After praying, a calmness came over me and I left my office knowing that no matter what was in store, I would need to be strong and that was all that I needed to know at that time. The rest of the day and the weekend ahead would be one minute at a time.

Our families went that evening to our daughter and son-in-law’s home to gather in support. I’ve never ordered so much pizza in my life! I remember that when I got to her home, I did not rush over to hug her like I so badly wanted to. We had things to

discuss and would need no tears for that. Once we were all there and had eaten over small talk, we got into the discussion of CCM.

Our daughter had found that in her searching a particular doctor's name was frequently mentioned or referenced: a neurosurgeon specializing in and concentrating on this condition. And this research ultimately led her to a website dedicated to this condition: the Angioma Alliance. Our oldest daughter had found the same website in her search efforts. They both had scanned the website and had much to say. We all felt a small bit of relief, if only for a moment. That small energy burst of hope was what we needed.

The girls talked about what they had found. My husband interjected at one point and said, "Wait. So, all three of my kids might have this? Okay well, if that happens, then I just want you to know that I can't handle it if you all have to have brain surgery at the same time. That's not fair to me to have to go through the worry. So, draw straws or whatever you have to do to take turns." We all laughed. Then our son said, "Well I am the golden child that will carry on the family name so I should get to go first." Then our oldest daughter said, "Well I'm the oldest so it should be me that goes first." Then our middle child said, "Well for once the middle kid trumps you both because I actually have it." And just like that we all busted out laughing.

This is us. No matter what was to come, we would do this together and with smiling cups half full. It's who we are. It's what we do. Bring it - but Lord don't leave us. Continue to be the light in front of us in this journey because we are going to need you. Amen.

### ***Perspective Shift***

I look back on that Memorial Day weekend of 2015 and I want it back so badly. But we know that we cannot go back in time and so things would change soon after that wonderful weekend and our lives would never be the same. Ever.

Our daughter was fortunate to have been accepted by the excellent neurosurgeon and his team. It was thanks to the Angioma Alliance and their website that we were able to access this crucial information. She consulted, went through testing, and had several appointments. Our daughter was put on the appropriate

medications for the different levels of seizure activity that she continued to have after having the baby. We began to absorb the reality that this was going to be something that would be prevalent for the rest of our lives.

By the late fall of 2015, we knew that this was not a sporadic case, but instead a genetic gene mutation: KRIT1. After conducting genetic testing for our granddaughter, our oldest daughter, our son, and myself, we found that we had two children and one grandchild with CCM1. With my having received the genetic testing and being negative, we knew that my husband had it also (but more about that later). This news was big so I called upon God to give me the strength for the time that it would take to fix this one, if it was even fixable. In 2016, I made the difficult decision to sell my business as it was too many hours away from our area considering I had three offices, over one hundred clients, and over eighty one employees that kept me busy twenty-eight hours a day, eight days a week and driving over one thousand miles per week.

While our younger daughter worked with the medical teams in Chicago to manage her seizure activity, our older daughter and our granddaughter showed no symptoms. Overall, this was not great, but we were steadily figuring out this new life with CCM1. We could do this. And we did, for multiple years. Almost long enough to forget.

In 2018, things changed again as we experienced our first “brain surgery.” Over the past two and a half years, our middle daughter had experienced “break-through” seizures. After several adjustments and increases in dosages of medication, it was determined that surgery would be the best option. The neurosurgeon said that the procedure barely made the list of termed brain surgeries because it would be so quick and simple. It was actually a procedure called an “ablation,” a newer technology to address cavernomas in the temporal lobe of the brain, which is where hers was. It would be done by a member of his team, not by him personally. I felt physically ill upon hearing that our daughter would be having not just a surgery, but a surgical procedure in the brain. Why was this happening? I had prayed. I had researched. I had made food from that damned cookbook for CCM. We were doing so well. Did our daughter not tell us that she had been having more seizures than we knew about? Was she not protecting her health while working? Did I not do enough to help her in her home, to

keep her stress levels low? Whatever the reason(s), I now needed to think about all of this differently. The surgery would be happening in October. Our rose-colored glasses were off. As a family, we were not getting through this without at least one surgery. And with those glasses off, I saw it in every set of eyes in my family: fear. And that was not something that we were familiar with.

My daughter and I traveled to Chicago and went into the hospital on a Monday with surgery scheduled for Thursday. With us being our usual “cup half full” kind of people, we laughed the very first day when we “scored” big with a Starbucks being right in the building. It was our sign that all would be well.

The plan was to place monitors on my daughter’s head and to have her go “cold turkey” off of the anti-seizure medications. This approach would “force” seizure activity and that activity could be mapped to confirm the exact lesion that was causing the breakthrough seizures. Watching my baby girl (twenty five years old, but still my baby) go through the phase of forcing a seizure truly hurt my heart. Also, because there was no sleep for her, of course, I would not be able to sleep either. I was her person and I vowed to myself that I would not let her down. But this was going to be rough.

By Wednesday morning, she still had not had a seizure. She was exhausted and started to melt - she missed her babies (three years and one year old, respectively) and just wanted to go home. In that moment, I could sense that a seizure was near. I could feel it. I knew what to do and I was willing to be “the bad guy.” I texted my older daughter and convinced her to FaceTime us (she had the grandkids while my son-in-law was at work, back in Michigan). The moment that my daughter saw her babies, she shattered. The guilt washed over me as I saw her pain. I knew that it would be months or years before either of my daughters would forgive me for this one, but it was done. The neurologist soon was in to confirm that a seizure had been documented (a small one, but enough) and it was, in fact, the suspected lesion. Surgery would happen the next morning. My husband, son-in-law, grand babies, and our son-in-law’s parents would be in Chicago before the end of the day, to be there for the Thursday surgery.

Once everything was confirmed, many professionals were in and out of the room, in preparation for the surgical procedure. All of them were very upbeat and warmly professional. At one point, a neurosurgeon from Germany came and asked our

daughter for her permission for him to accompany the team with the surgery. Cool, right? It's a learning hospital after all. But with my healthcare background, I took note of the situation and I was a bit more inquisitive as to exactly why he was there. I later found out that this particular procedure had been done less than a handful of times, so I believe that may have factored into his having been there for this particular procedure. Wednesday came to an end and although I wanted to be with my daughter every single minute, I had to step back and out of the room to give her time to be with her own little family, once her husband and their two children arrived. Then we parents and parents-in-law said our good nights and took the grandkids to the hotel. Our son-in-law stayed until the end of visiting hours that night. Tomorrow morning, my baby girl would be having brain surgery.

Thursday morning came. The surgeon came into the room and told us that the surgery would take eight hours, with two drills and minimal hair removal, as they could just take hair in the drill areas. My daughter was glad to hear that because she had every intention of being at an interview for a promotion/new position at work, the following Monday. The surgeon had assured her that would be possible if all went well. After he left the room, we said our "love you" and then to the waiting room we went. Our son-in-law had the notification device in hand. Although every minute seemed like an hour, shortly after the surgery was scheduled to start, the device lit up - way too soon. It took everything in me to stay seated in my chair to let our son-in-law approach the desk while I waited. He came back to where we were all seated and said that they had to take her out of the OR and re-drill because they could not get to the lesion from the first drill attempt. My stomach dropped. I thought this was going to be easy. My doubt, panic, and anger began to rise and that ill feeling was coming back. NO, this is going to be okay. I had to stay calm. Although praying helped, the rest of the wait was grueling. At almost the exact time of the original promised procedure end time, the notification came that she was in recovery and that our son-in-law could go to her. It killed me to not go to her right then, but we parents waited. We were soon able to take turns going back to see her in the recovery room. When I saw her, I was instantly shocked to see that half of her hair had been shaved. Oh, my girl was going to be so upset about that. The interview, sigh. Isn't that crazy that this was my first thought when seeing her? I needed to let go of these small thoughts and be praising God that

all had gone well and my baby would be okay. With the relief of the procedure being over and continued assurances that all had gone well and her recovery was right on point, my husband and I drove back to Michigan on Thursday night. Our son-in-law's parents stayed to help with the grandkids and the logistics of the drive home. The surgical team presented on her case the very next day after a short stop in her room and amazingly, everyone was back in Michigan by the next evening.

When arriving home, I knew that I needed to look at things differently— to shift my perspective. I needed to be better prepared for the next time, if there would be one. And there being another one was more likely, in my mind, with having four members of our family with this rare condition. So, it was time to switch gears, but I would have to handle a few other things first. Like what my younger daughter was okay with me sharing with my oldest daughter and or anyone, about the hospital and surgical procedure experiences. How much of it was my oldest daughter going to want to hear or know? Since my children were small, we had shared almost everything and yet I could tell that it had been different since CCM had entered our lives, with one child symptomatic and one not, and the third child not having CCM. I knew that I had to be in different support roles for each family member, moving forward. Our son-in-law had been so strong the past three years since the diagnosis, but how much could he take? I know as the wife, mother, and grandmother that I was constantly worried, which caused many hours and days of mental exhaustion. Knowing this, I was certain that he felt as much worry, or more so, as I did. Supporting everyone in each person's needed way would be a challenge, to say the least. In addition, my husband needed to know that he was the parent with the KRIT1 gene mutation. I cried when thinking of all of these things, but again fell to my knees in prayer. And with that, my tears stopped.

Looking back, I did feel a sense of calm, overall, for that first surgery. A feeling that was similar to the calmness that day of the first diagnosis. Moments of panic came and went over the next few years, but they were very quickly replaced with that sense that all would be alright, somehow. I do not believe that would have been the case had I not continually prayed, meditated, and found my way back to the half-full cup mindset and lifestyle. Things changed for our family, in 2018. No more rose-colored glasses,

but rather just clear lenses as we resolved that we would navigate each day as it came and learn to live with CCM1.

### ***CCM1 in the House***

Some may find it strange, but for the first three years after we found out about CCM1, we really just settled into living life daily without letting this new knowledge consume us. As I write this, however, I am positive that was not the case for our middle child. She was living with breakthrough seizures, medication changes, frustrations with doctor's appointments that would constantly be rescheduled, making a mess out of her carefully curated timeline for efficient travel to another state. Her well-planned attempts to take as few trips as possible for her healthcare and to limit her time off from work were constantly being thrown into disarray. In addition to all of that, she and our son-in-law had a second child. So, I am going to just put this into print: it often felt like it was her "fault" that we forgot about CCM1, during those first few years.

Our middle child did not complain, nor did she ask for help, nor did she lament about her condition. She just quietly soldiered through. But it was also our oldest daughter's "fault." She dove into the research and did what she had to do to be as proactive as possible and she was the same as our younger daughter: no complaining, no lamenting, and no heart-to-heart chats with me about CCM1. She did and does protect her peace and that usually meant that she was not very open for any kind of CCM discussion. I'm quite confident that my daughters' husbands would not interpret their actions in the same way that I did. But the husbands obviously occupy a different position than that of a mother who tends to be fiercely protective of her "babies." They are both amazing care support partners for their wives and that helps my heart stay full.

After the 2018 surgery, life with this illness became more real for all of us. Before then, I had gone to the Angioma Alliance website on and off, I but had never really dived deeply into the material. In retrospect, I think this was because I still did not want the situation to be real and also because— given the extent to which it was affecting my entire family— I was something of an emotional mess. I had four people in my immediate family with a rare condition that there was no cure for.

My first real attempt at gaining control of my mind with this was attending a webinar about how to talk to children with CCM. I think that I held it together for the bulk of the webinar, but I cried afterward. The stories of other children and their very active journeys was heart wrenching. The following morning, while at my daughter's home to help with the kids' transport to school, my then six-year-old granddaughter asked, "How did your meeting go last night?" I had to think for a minute and then replied, "Oh it was fine." To which she replied, "Well, what did they say?" My mind reeled. Umm . . . how much did she know? How much should I say? I am not her Mom and I had not spoken with her Mom to know what she wanted me to do with the information that I had.

I had been berated so often for saying the wrong thing to the wrong family members when trying to discuss anything CCM-related in the past few years that I did not know what to say in that moment with my granddaughter. Well, we stood there in the dining room of my daughter's home looking at each other for a moment and then I explained it to her in the way that I had heard the night before with cavernomas having a raspberry like appearance and when they get too juicy, they burst. My granddaughter crinkled her nose and replied, "Well I never want to eat a raspberry again! Why not just say that they are blood vessels that hemorrhage?" I sighed and replied, "Gosh, I don't know. Maybe not all children in the first grade are like you and have a Mom like yours." I should have known better! She's just like her mother in this way (and how I raised all three of my children). Honest and to the point no fluff transparency with the "clear is kind" mentality. I was both proud and yet sad at that same time. Of course I wanted her to understand, but also how absolutely heart breaking for my granddaughter to have to handle such a heavy subject, at her age.

After that little exchange with my granddaughter, I can tell you that I knew that I needed to be a bit more "in the game," if I were going to be prepared for what would come our way with CCM! So I dabbled more and more online to gain further knowledge. But my attempts were often foiled by frustrating responses from my children. For instance, I would try to talk to my family about it only to be told that I had something wrong. I would speak of something that I remembered from a doctor's appointment or something that one of the girls had told me, only to be told that I remembered the details incorrectly or that it just looked like I made things up.

I would feel dejected by the distance that my daughters gave me as they shared their experiences and conversations with their husbands rather than me. Not that they should not have shared with their husbands; but with my personality being someone that needs to be needed and wanting to give of myself one hundred percent to my children, it hurt. So, I stopped trying. This wasn't what I wanted to do, but something I needed to do for my own emotional protection.

And as for my husband, well, he never got an actual genetic test to confirm that he had CCM1. He did not want to know. His mother, brother, and sister had ALS and with that having no cure, he knew what they had gone through mentally and he did not want to live like that with CCM1 not having a cure either. It would be nine years of not discussing CCM1 with my husband as he did not know that he had it and would not talk about it. Period. Between my daughters distancing themselves from me and my husband refusing to test for the gene that, deep down, he knew that he had, I was living daily as a highly functional person with depression. I don't have a prettier way of saying that. And so it would be for the next several years. . . .

By the fall of 2019, my daughters and I were slowly getting "back to normal" with our relationships. By trial and error, I was learning what I could say to which family member about CCM and what I could not say to each family member with CCM. Our son and sons-in-law were support members in the journey and I frequently chatted with them about things as support family members. That helped me feel that I was involved even when I was not able to talk directly about CCM to my daughters. I was helping my younger daughter in the home, with our grandchildren, so that she and her husband could work and not have to put the kids in daycare.

In May of 2020, Michigan experienced excessive flooding that caused four of our local dams to fail. Our middle daughter's home was along one of the rivers that had catastrophic flooding as a result of those failures and the whole basement of their home flooded. Shortly after they were able to return to their home and had started the clean-up and repairs, she wanted to go to the place where they had purchased many of the customized Christmas ornaments and get them replaced, if possible. She was so set on going immediately that I was worried. I asked her about it and her reply was that she needed to get them replaced as soon as possible because she lives a life of not

knowing if she will “be here tomorrow.” I stopped breathing for a moment, recovered, and then we went that day to the nearby city of Frankenmuth where the ornaments had been purchased. The frankness of that one statement from her changed me, again. Although on the surface we all looked fine, we were not. This shit was real.

Then on an early morning in December of 2022, while on the phone with my oldest daughter, I received a phone call from my husband’s oldest niece. I told my daughter that I would have to call her back because there must be an emergency as our niece was a kindergarten teacher and given the time of morning that it was, she would have been at school already.

Our niece was looking for some help with information about CCM. Her son was in the hospital and after multiple tests and procedures, the pediatric neurologist stated that they may be looking at a cavernous malformation. Our niece and her husband disclosed to the doctor that our family had the condition. As a result of that phone call, genetic testing was done, CCM1 was diagnosed, and our great nephew had a craniotomy at age three later that same month. Within a few short months following that winter surgery, we had three more diagnosed members of my husband’s family, with CCM1, and my husband finally came to the realization that he had it, also. But what would he do with that confirmation?

### ***Medical Misadventures with My Husband***

My husband chose to let one day turn into a week and then a month and so on, with doing nothing about his CCM. He did have occasional mood swings and “spells” that our younger daughter told him were most likely auras (a form of seizure), as his descriptions fit similarities of how hers felt— and, at that point, she had had many auras over the years. We, as a family, tried to persuade my husband to not only go to get diagnosed for his own health, but to consider the diagnosis to be ready to assist in any future research or studies that might be a good fit with considerations to our families’ cases. None of our encouragements were acknowledged.

My husband has never liked going to the doctor. He has always said that people go to the doctor then they die. His reasoning has always been based on the memory when he was seven years old of his father going to the hospital after having severe

headaches, to being hospitalized for two months with an unclassified brain tumor that burst, with severe hemorrhaging causing complications that would lead to his death. We will never know if that was, in fact, a cavernoma. While I can empathize with that, I am so very thankful that our children grew to be adults who did not believe that approach to be the correct thought process for healthcare.

He retired in October of 2023. By November of 2023, he was hospitalized due to an infection in his foot. While in the hospital, he had many tests and an MRI. It was determined that the micro bleeding in the brain that they saw in the MRI was due to chronic atrial fibrillation as well as chronic high cholesterol, which were determined from other tests and procedures. We disclosed that he had CCM. The neurologists at our local hospital did not have knowledge of CCM and so were not able to address any of the symptoms being from CCM. In addition, they refused to refer us to a neurologist or neurosurgeon for CCM because with them not suspecting it to be so, they would consider my husband to be non-compliant if he did not accept the medical treatments and medications as they advised. So after five days in the hospital, he was sent home to finish the six weeks of the IV antibiotics and wound care for the foot.

I can tell you now that I have absolutely no memories of any laughing during those six weeks, but we did stay married. I am not confident that would have been the case if I would have been in charge of his home care. I would love to insert a “LOL” at this time in this story, but that would not accurately describe how I felt! I had even started sleeping in a different bedroom due to his sensitive foot and although I thought that would bother me, it absolutely did not. But by the end of the home therapy, he was walking on his own and it looked like his foot would make a full recovery.

A week after his IV therapy was completed, my husband and I were constructing a walk-in shower at our son’s newly purchased home, as part of the renovations. I remember standing in the shower, grouting the tile on the walls, while my husband sat on a five-gallon drywall bucket. We were talking about his uneven pressure when grouting compared to my even pressure and he was teasing me that this was how he was building me up to finish the job so that he would not have to. I said laughingly, “So are you saying that I do a better job than you, the big commercial contractor superintendent? I find that incredible for you to admit that.” To which he replied with

nonsensical slurred words. I turned around to look at him and he was slumped over with his head in his hands. I spoke his name and he looked up at me with a glassy look and slurred more words. I asked him if he was talking about our son and he said, "Yeah." I stepped toward him and he then said, "Wow, I'm having one of my spells." I agreed with that, but also thought to myself, "this has never happened." We have gotten to a new level of spells, for sure. I got him a glass of cold water, then grouted to where I could walk away and we went home. By nine o'clock that night, he had another spell, but it was more of what he had been used to for years. He went to bed shortly after that and was sleeping soundly within minutes of his head hitting the pillow. So, all seemed normal again, at that point.

At 2 o'clock on the morning of January 2, 2024, I woke to a huge thudding sound. I listened for a second and then heard a duller thud. Then another. What in the world was that? And what do I do now? I go to get my husband, that's what I do!

As I rounded the corner of the front hallway on my way to the back hallway to the master bedroom, I almost fell over my husband. He was on all fours like a child doing the crab-walk. I asked him what was going on. His head turned my way, but there was no focus at all. He was breathing so rapidly and loudly that when I put my hand on his chest, it felt as though his heart was going to pop through the skin at any moment! I said, "Wait here. I am going to get my phone and call for an emergency." As soon as I turned to do so, though, he flipped on his hands and knees and almost knocked me over as he crawled faster than a spider trying to get away from my shoe, down the front hallway to the front living room where he then tried to climb the fireplace wall like Spider-Man. Thankfully, the television over the fireplace is secured to the wall with a bracket. I called out his name as I caught up to him and he then proceeded to almost bounce off from all of the furniture as though they all had force fields on them to repel him. Finally, he threw himself on the loveseat. I said again, "Stay here, so I can get my phone." He held out his hand toward me saying a panting version of "I love you" over and over. At that moment I had two thoughts. One was that he was cognitive enough to know what was going on and he might be having a heart attack. Two was that I sadly could not let him take my hand so that I could comfort him or let him grab me or else I would most likely not be able to get to my phone. I turned to go to the front bedroom a

second time to get my phone, but before I had taken two steps he jumped up from the loveseat and ran down the hallways to the master bedroom and flung himself on to the bed. Okay, I had time to get my phone, so I went to the front bedroom and grabbed it and then ran with it, back down to the master bedroom, while calling in the emergency. He was on his side and still radically breathing.

What was happening? I'd never experienced nor heard of anything like this! While on the phone with emergency services giving them the needed information to get to us, I spoke to my husband as his breathing seemed to be less erratic. I asked him if he knew my name. He slurred something like "Glenna". I asked, "Glenna?" He said in slurred speech, "No, Linna". I asked, "Linda?" He replied, "Yeah". The responder on the phone asked me if that was correct to which I said, "No, neither of those are correct, but we will have to deal with that a different day." Appropriately, the responder did not laugh. That was good material there for some comedian somewhere and I am sure that it came out because I needed something to laugh about so that I didn't crumble, so I did laugh a little.

By the time the ambulance got to our home, my husband was asking what was going on. He understood that he needed to go to the hospital, so he went. After he was wheeled out of our sliding glass door of the master bedroom, I went to close the door and lock it before I would then follow the ambulance. As I approached the door, I saw smudge marks on the glass, higher than my face level. What was that? The realization hit me. Those were marks from my husband's forehead. The dull "thuds" must have been him trying to walk out the door while it was closed! What in the world?

What we found out in the next two days was that my husband had had an ischemic stroke, a hemorrhagic stroke, and a grand mal seizure simultaneously. Again, with no formal diagnosis, our local hospital refused to discuss the possibility of CCM and again attributed the events to being related to his chronic atrial fibrillation and chronic high cholesterol, in addition to adding the citing of a history of heart attacks based on test results. He was placed on anti-seizure medications. By the second day, my husband declined further treatment and requested discharge from the hospital due to concerns that the needed MRI testing could be denied by our insurance unless we

could first get in to the appropriate specialists. My husband went home on January third and his journey of being frustrated with the medical field only increased.

Over the next several months, my husband was seen by a local Family Nurse Practitioner who referred him to a specialist. To this date, I am not sure exactly where things got off track from that referral, but it was a blur of confusing transactions that ended in a heap of frustrations and no answers. No one seemed to want to hear, understand, nor assist us with a CCM diagnosis. None of which helped at all with my husband's predisposition with the medical field. And so, our summer went, with my husband feeling well on again and off again, but with him continuing to refuse to go through "all of that again".

### ***From Darkness to Light***

In late fall of 2024, our granddaughter started to have intense headaches. My daughter and son-in-law had, since 2023, been taking her to Ann Arbor to the pediatric neurologist that our great nephew had seen, but they also stayed with the neurosurgeon in Chicago. It was in December that our granddaughter had her first MRI. While driving home from that annual check-up appointment and MRI procedure, the phone call came. And from that call, we found out that our granddaughter had five cavernomas— and one may have recently bled or may be currently active.

The neurologist said a few things that concerned my daughter. She decided to wait to hear from the neurosurgeon's office once they had received the MRI results and reviewed them. After two weeks, my daughter called the neurosurgeon's office to find out that they had not received the communications. Mama bear mode kicked in and everyone backed up while she took care of business in getting our granddaughter switched back to the pediatric neurologist in Chicago as well as being seen by the neurosurgeon as soon as possible.

By April 2025, at the age of nine years old, our granddaughter had a craniotomy to remove the cavernoma that was quickly growing and actively bleeding. My husband and I went to Chicago on the day of the surgery. We came home that same day so that I could help with the pets at their home while they stayed in Chicago for a few more days. At one point, when at their home, I just broke. I cried so hard that I felt like I was

outside of my body hearing someone else crying. It felt as though I had cried for hours, but I believe it was only minutes. I prayed out loud in a language that only God himself could have understood because my words were spoken through wracked sobs and definitely were not coherent enough for a human.

When I stopped crying and blubber praying, I took a breath and there was that calm again that I had experienced so many times over the past ten years. I was over it. Everyone in my family was so strong; I never heard of them crying like this. I then realized that I was actually lucky that they did not seem to need me like I had been grieving about. So maybe it was time to let them handle their CCM the way that they needed to and I should do something for myself, as my focus.

Why had I not previously thought of what I needed? After all, I've been in this, too. And better yet, if I really want to be needed, shouldn't I be asking a better question? Shouldn't I ask, "what is the thing that my family, as well as others with CCM, truly need?" They need this condition to be canceled. Cured. So, if my family could be so strong why couldn't I? I got my iPad out and I went online. Angioma Alliance was now Alliance to Cure and they had a click button to volunteer. How easy was that!

### ***I am In This, Too***

So here we are, ten years into this journey and I'm so glad that I clicked that volunteer button on the Alliance to Cure website in April of 2025. Since that day, I've had such fulfillment in my head and in my heart. I am so happy to be able to help the Alliance to Cure in whatever ways I can, to move forward with them in raising awareness and finding a cure. And guess what? We, as a family, have grown so much this past year; in knowledge, awareness, advocating, and how to better live this journey. I no longer feel insufficient or in the dark when considering CCM in our lives. I am confident that I am doing my best to help with both raising awareness and finding a cure. It's the best help that my family can receive, and my life feels full of purpose to be able to continue my nurturing role in our family dynamic.

But also, I have come to realize that I am in this, too. Sometimes it's about me and my journey. So many days during those ten years, I was hanging on for dear life caught up in my emotions and feelings of failure and inadequacy. I went too long feeling

as though I had failed as the nurturer. It seems so silly to me, now. Those feelings not only did not serve my family, they also did not serve me. There was nothing productive in those feelings. I am not saying that they were not valid at the time – because, of course, they were — but rather, that I am so thankful for those low moments because I needed to experience those to learn how to process them and grow. My cup stays half full now. I am not foolishly thinking that I will not have hard days ahead. But I will handle them differently. And there will be many good days. But no matter what kind of days are ahead, we will take them one day at a time. We will find a cure. Together, with the grace of God.



# Life, Loss and Living with CCM

By: Taylor VanZant

## *Pre-Diagnoses*

My story before my diagnosis was not one free of hardships.

At the age of three or four, I realized what mortality was. I was at a Mother's Day breakfast at my preschool, eating a ton of chocolate (my favorite indulgence), when I suddenly passed out and awoke in a janitor's closet. It happened again while trying to learn how to ride a bike when I skinned my knees on the harsh concrete outside my childhood home. The sight of the blood made my face and lips turn pale, and I would pass out, especially whenever I got overheated in the harsh Florida sun. 'Losing consciousness is what dying would be like,' I thought to myself during those young and formative years of my life.

My childhood wasn't always scary, though. I have such fond memories of my innocent youth. I grew up with a nice big yard in a lovely house where I would run, play, and swim all summer long (while always being careful of the heat, of course). I had the wildest imagination and would come up with the craziest games with my two very best friends. Above all, I loved my dogs. All eight of them (yes, eight!) My parents and I would make a bed on the living room floor and watch movies, especially during the Christmas season. My sisters would always come over early in the morning and watch me open my Christmas presents. I had three older sisters: Lindsay, Kristen, and Harmony. They are much older than I was, and I always looked up to them, constantly wondering what it would be like when I was their age. I always wished I could grow up faster. Watching old home videos brings back memories of those simpler days. The world always had a warm hue, and I felt safe and secure.

Things changed when I entered elementary school and dealt with bullying. In the second grade, someone put a cookie with a worm in it in my lunchbox, and I wondered how a person could hate me so much. I was always friendly to my peers and an outgoing kid, always making teachers laugh and trying to cheer others up when they were sad or upset. I was a good student with all A's and one B in math. To this day, I struggle immensely with numbers.

In fourth grade, my grandfather passed away. I called him "Gramps." He was having open heart surgery, and I remember telling him, "You're going to be okay, Gramps." He replied, "I know, sweetheart." Those were the final words I ever spoke to him. After his death, my life changed drastically. I started having vivid night terrors and missing school more than usual. A lot was going on in my home life at the time. I began to develop a debilitating fear of death. I had

already lost a lot of loved ones, but the death of my beloved Gramps was sudden and beyond heartbreaking.

In middle school, I struggled with my mental health a lot. Depression had taken its toll on me like a black cloud. People used to ask me if I was sickly or ill because of the dark bags constantly under my eyes. I was not doing well. However, those are the last years I can remember that felt somewhat "normal."

During the start of my first year of high school, my eldest sister, Lindsay, was diagnosed with a rare form of cancer called lymphoblastic leukemia. It rocked the foundation of my entire family. She was the best of all of us, always charitable and kind, but would tell you the truth in a heartbeat, even if it was harsh. Her life cannot be summed up in so few words. I could write an entire book just about her. She was the strongest sister, and we were more than confident she would beat it against all odds. So, when she went into remission, we were beyond ecstatic. Then, things took a turn following a bone marrow transplant. We lost her, the glue that held us all together—the one who would plan all of the family gatherings. I was fifteen at the time and struggled to come to terms with the fact that she would never see me grow up.

Following her death, I became very numb to cope with the loss. People often say that time heals all wounds, but some scars are so deep that they leave a hole in your heart that can never be filled, no matter how hard you try or what you decide to fill it with. I had a few rebellious teenage years, but eventually came to terms with the reality that life can be difficult and unfair. I started developing horrible health anxiety. Every ache, pain, or labored breath I thought was cancer. I always felt like something was wrong, but could never quite figure out what.

Years passed, and things started to improve. My depression was not as severe or debilitating, and I began to live my life fully, knowing that's what my sister would have wanted. I even met someone to share life with, despite all its ups and downs. Since I was a little girl, I've always been sure I wanted to start a family early. I assume this is because I've been shown that a long life isn't always promised. My life finally felt like it was on the right track. Everything was falling into place perfectly. 'Everything is going suspiciously well,' I kept thinking to myself.

I don't like being a pessimist or having a negative outlook on life. I think a forever sense of impending doom is a trauma response I've developed due to the things I've witnessed and been through.

It helps me stay realistic and not get my hopes too high, and prepares me for what's to come.

## Diagnoses:

When I awoke in the early morning hours of September 24th, 2024, my right side was completely numb from head to toe. I thought my body had just "fallen asleep," and I shook about wildly in an attempt to "wake it up." However, this was a nightmare I couldn't wake up from. I rushed to the emergency room in a panic. Being a young and healthy-looking woman has always been an invalidating experience when seeking medical care. They told me it could just be a bad migraine, and as much as I wanted to believe that, I knew something was horribly wrong.

I had never had an MRI before, despite the numerous times I had hit my head on the concrete, tile, or hardwood floors from passing out. After I came out of the MRI machine, I saw a group of doctors behind the glass whispering in hushed tones. Something wasn't right. They told me I had to go back in the machine for another MRI, but with contrast this time. It took every ounce of strength and courage within me not to move during that second MRI. I listened to the clanging, clashing, whirring noises surrounding me with tears steadily streaming down my cheeks. When it was over and everything fell silent, I crumbled. I started to have one of the worst panic attacks I've ever experienced, and every second felt like hours passing by.

Around forty-five painstaking minutes after being returned to the room, I was told they had found a mass on my brain. I immediately asked, "Like the C word?" The "C word" is how we have referred to cancer in my household since the passing of my sister. They told me, "Most likely yes." In the following moments, I saw my sister's life flash before my eyes. I knew what was to come if that was the case, as we had been through this before—chemotherapy, constant sticking and poking and prodding at the body, loss of appetite and weight loss, and clumps of hair falling out each day. My sister will always be the toughest person I have ever known, and I knew I could not fight the way she had. I didn't have it in me.

Both of my parents were out of town at the time, and I quickly realized I had to call them to share the news I had just heard. How was I going to tell my father that he could potentially lose another child to cancer? I could hear the lump in his throat form when I told him, and how it went down into his heart and sounded like it might come back up as vomit. They both hopped on a flight straight away.

Out of all the things I thought were wrong with me, I had never suspected my brain. I have always been emotionally intelligent with a sense of book and street smarts. I have an affinity for language and words, and love reading and writing. I crave knowledge and began indulging in philosophy and spirituality as a preteen. I am a being that craves knowledge and wisdom above all else. I am always trying to educate myself on a wide range of topics.

Another doctor came in and told me they could biopsy the mass in three days, or I could get a second opinion. I wasn't going to let some random person dig into my brain, so I decided to go elsewhere. After more scans and another MRI, I was told the following day that I had a different kind of "C word," a cerebral cavernous malformation. The entire room, filled with my family, friends, and me, took a collective sigh of relief. Then we realized, what was this diagnosis, and what did it mean? I had never heard of this disease, even after all my late-night Google searches of my symptoms and self-diagnosing (terrible, I know.) We found out I had a brain hemorrhage and that surgery wasn't a good option for me. The mass is large and deep in my brain, making it difficult to access. I would come to find out later on, following a brain mapping MRI, that it is pushing on my corticospinal tract, which controls voluntary movements. If the blood had gone a few centimeters further inwards, I would have been paralyzed on the right side of my body.

#### **After diagnosis:**

The only information I was given was to go home and "live my life." That was easy for them to say, of course. The doctors weren't the ones who had just been given this life-altering diagnoses. I didn't know what to do with this information or how to move forward. Waking up every day, I was dealing with a constant reminder of what I had just been through. The headaches felt like knives going into my skull, and the nerve pain was unbearable at times, as if I was stepping on a bed of hot coals, and vision changes that made it hard to go outside and enjoy the sunlight or watch any of my comfort shows. Every sensation was uncomfortable and new. It felt like I had just been reborn in a body that no longer felt or worked the same. The sensation of a blanket rubbing my leg felt like sandpaper, and the warm, comforting, refreshing stream of water from the showerhead felt like tiny needle pricks against my skin. Loud noises made my head feel fuzzy and would completely disorient me.

Despite all of these symptoms, I felt as though I had been given a second chance. I was already well aware of how precious and fleeting life can be and how easily your health can be stripped from you, but it was I who was affected now. I woke up with a newfound sense of gratitude that I had never before experienced. I thanked God every day for the ability to walk, talk, breathe, and see. I realized how many people take those simple things for granted, even myself. I vowed to go out and create new experiences and have the most fulfilling life.

In early October, I had my second bleed. After a physical therapy appointment, I felt incredibly off. Was something wrong again? It is hard to trust my body now, but I had been doing so well and had a good mindset. I was trying to eat healthier and watch what I consumed and put into my body. I had been living my life just as they had said to do, and was trying my

absolute hardest. I realized the severity of my situation and that some things are just not in our control.

The following months were some of the worst moments of my life thus far. I spiraled into complete and utter darkness. Every night, I was terrified to go to sleep and would wake up in a full-blown panic. Every new or slightly changing symptom petrified me. I was scared to move too quickly and get my heart rate up too high. I was frightened of every bump I would go over in the car, thinking a sudden jolt could cause another bleed. I was afraid that if I lifted something too heavy or got too anxious, stressed, or upset, this thing inside my head would just burst. I thought that maybe, just maybe, if I lay in bed and stay motionless, I could prevent anything else bad that could happen to me.

After some time, I realized this was no way to live because it wasn't living at all. I was only existing and consumed by existential dread. Death is something I have always feared, but what I was doing to myself couldn't have been much different from death itself. At least death would be potentially freeing from no longer being in pain or suffering, but I was letting that anxiety, worry, and fear suffocate me.

I felt like I had regressed into a child again, and this time, I didn't want to grow up quickly. I was living with my parents, and they were helping feed me, bathe me, and console me to sleep at night. My life had taken one gigantic leap backwards in the matter of a few months. I was no longer interested in making plans because the future seemed too uncertain even to consider. It was much too risky to think that far ahead.

The relationship I was in at the time had turned very toxic, especially following my diagnosis. Arguments became more frequent. The constant anxiety and stress this caused, along with CCM, was too much for anyone to bear. However, I understood that my situation was difficult to handle because I was the one going through it.

Navigating that season of my life was incredibly difficult, and eventually, once I was well enough, I had to end that relationship for my own mental and physical health. I was overcome with grief, dealing with so many losses and life changes during such a short period of time.

***Current:***

Now on my own, I was able to focus on myself fully and decide how to move forward. I became more involved with the Alliance to Cure Cavernous Malformations by attending support groups and connecting with others who have CCM. I met so many wonderful individuals in this community. It is an understatement to say that I couldn't have made it through navigating this diagnosis without them.

I started living my life again as normally as possible. I've been able to visit amusement parks, ride some rides, and enjoy haunted houses (this is an annual family tradition.) I've met new people, tried new things, seen new places, and found my spark for life again. I've read new books, found new songs to sing, and have made so many amazing memories. I even traveled to Canada, which was a massive win for me. I am beyond blessed that I am still able to do things that brought me joy before finding out I had CCM. I plan to continue doing things that make me happy and spend time with those I love and who love me.

As of now, my future, while still unknown, isn't as far out of my reach. A cure is on the horizon, and I've found a sense of purpose in aiming for one. My family and I hosted an auction in November of 2025 to raise some funds for the Alliance to Cure. I shared my story and met other people with CCM in person. It was a healing and much-needed experience for me. This is why I've decided to share my story now, in hopes that it will raise awareness, shed light on this disease, or help someone feel less alone.

While my life is not what it used to be, and I continue to grieve past versions of myself, I am thankful for the lessons I've learned. I've grown so much, in so many ways, over the last couple of years. If the newly diagnosed Taylor could see where I'm at now, she would be really proud of herself, and that makes me incredibly happy.



## ***With Gratitude***

Our heartfelt thanks to the writers who shared their journeys and made this collection possible.

We are especially grateful to Kristen Fowler for keeping the group organized throughout the year, and to Rebecca Kneale Gould, whose editing was indispensable in shaping these stories.

And thank you for reading, for taking the time to sit with these stories and be part of this community.

This project was created through a community writing group hosted by the Alliance to Cure Cavernous Malformation. We are proud of what was built together and of the growth that unfolded along the way.

We plan to host another writing group in 2026. If you feel a story stirring, we would love to welcome you. Email [info@alliancetocure.org](mailto:info@alliancetocure.org) to learn more.

To learn more about CCM, find support, or connect with future projects, visit: [AllianceToCure.Org](https://AllianceToCure.Org)